

**“Young Men and their Parents Views on
the Impact of the Diagnosis of Asperger
Syndrome on their Educational
Experiences.”**

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**A thesis submitted in partial fulfilment of the
requirements of the University of East London
for the degree of Professional Doctorate in Applied Educational and
Child Psychology**

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STUDENT DECLARATION

Declaration

This work has not previously been accepted for any degree and it is not being concurrently submitted for any degree.

The research is being submitted in partial fulfilment of the requirements of the Doctorate in Applied Education and Child Psychology.

This dissertation is the result of my own work and investigation, except where otherwise stated. Other sources are acknowledged by explicit references in the text. A full reference list is appended.

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ABSTRACT

In this qualitative research, I was keen to explore the experiences of young adolescent men diagnosed with Asperger Syndrome and the impact of having the diagnosis on their educational experiences. This study is unique because, although much research has involved the views of adults with Asperger Syndrome and the experiences of parents on the assessment and diagnosis of their sons, little research has been undertaken regarding the experiences of young men themselves.

In order to facilitate the young men's voices I elicited the support of the mothers as co-researchers and participants in the research. Semi-structured interviews were conducted with eight young men, eight mothers and three fathers (who also participated in parts of the interview). The research also involved considering the experiences of mothers on the journey to have their son's needs diagnosed and the support provided to meet educational needs.

The data was analysed using Thematic Analysis. Three themes emerged, including families' experiences obtaining the diagnosis; families' experiences of education following diagnosis and the young men experiences.

This research produced a range of insights about the experiences of having a diagnosis of Asperger Syndrome and the impact of such on the educational experiences of this group of young adolescent men. It highlights the importance of understanding the relationship between sons and mothers and the need for Educational Psychologists to develop skills in promoting the voices of young men diagnosed with Asperger Syndrome, in line with current legislation.

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LIST OF ABBREVIATIONS

ASD	Autism Spectrum Disorder
AS	Asperger Syndrome
EP	Educational Psychologist
EPS	Educational Psychology Service
Ext.	Extract
LA	Local Authority
LEA	Local Educational Authority
NAS	National Autistic Society
NICE	National Institute for Health and Care Excellence
SEN	Special Educational Needs
TA	Thematic Analysis

1. INTRODUCTION

1.1 Overview

This research aims to explore the experiences of parents and young men diagnosed with Asperger Syndrome (AS) in order to gain an insight into what they have experienced in terms of the diagnosis itself and its impact on their secondary mainstream education.

This chapter aims to provide the background, context and rationale for this research. It begins by exploring the terminology used in Autism. Diagnostic criteria will then be reviewed followed by an overview of the issues related to Autism. The researcher's position and justification for the research is then described. The chapter ends with the consideration of the distinctive contribution that this research offers to professional practice.

1.2 Terminology

Autism

Kanner (1943) laid the ground work for diagnosis and assessment of children with Autism who had previously been diagnosed by the psychiatric community as having childhood schizophrenia. Kanner coined the term "early childhood Autism" which encompassed both the time when characteristics of the disorder began to be identified as well as the difficulties with development of socialisation. Kanner identified a number of key characteristics of the disorder that could be summarised as a profound withdrawal, a great desire for sameness, a good rote memory, lack of language or language without

communicative intent, over sensitivity to stimuli, such as having an exaggerated emotional response to loud noises and a preference for spending time in solitary play activities with objects.

Asperger Syndrome

The use of the term Asperger Syndrome (AS) refers to individuals with some autistic features who may not fit all the criteria for Autism. Children originally described by Asperger (1944) were characterised by pedantic and stereotyped speech, clumsiness, obsessional interests and deficient social behaviour. Wing (1981) brought Asperger's work into the mainstream and noted that both Asperger and Kanner described many similarities in their clinical accounts and raised the question as to whether they were describing the same condition with different levels of severity or were these two distinct conditions. The term Autistic Spectrum Disorder (ASD) was constructed to conceptualise this (Wing, 1981) with Autism being placed at one end of the spectrum and AS at the other.

Autistic Spectrum Disorders

Wing (1981) points out that there are no medical tests that can determine whether a person has an ASD. The diagnosis is generally given when an individual displays a number of characteristic observable behaviours indicative of problems in social interaction, communication with a very restricted range of interests or pattern of behaviours. Wing has referred to, in the literature, a 'Triad of Impairments' and advises that the degree of severity in the Triad can vary widely from individual to individual. Further she recognises that

individuals with ASDs may also display a range of associated difficulties including hyperactivity, short attention span, impulsivity, aggressiveness and clumsiness. There may also be strange responses to sensory stimuli such as oversensitivity to sounds, being touched, exaggerated reactions to light or odours, low pain thresholds and/or fascination with certain objects (Wing, 1996).

1.3 Diagnostic Criteria

ASD and AS were originally included in the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition DSM-IV (American Psychiatric Association - APA, 1994) under the umbrella category of Pervasive Developmental Disorders (PDD). However recent changes in the diagnostic criteria has meant that ASD only will be used to include other conditions which were previously identified independently including early infantile ASD, childhood ASD, high-functioning Autism and AS (DSM V, 2013). ASD is now defined in the DSM V by persistent deficits in social communication and social interaction across multiple contexts; restricted, repetitive patterns of behaviour, interests or activities.

Prevalence Rates

The acceptance of the concept of ASD and the consequent rise in the number of people diagnosed with ASD has led to controversy as to whether the true incidence of ASD is increasing or whether diagnostic practice and broadening of the concept is resulting in the diagnosis of cases that would previously have gone unidentified. In the United Kingdom there is a reported increase in

numbers of pre-school children being identified as having an ASD (Rutter, 2005). Baron Cohen, Scott, Allinson, Williams, Bolton, Matthews & Brayne (2009) report prevalence estimates for ASDs in the UK school population to be 15.7 in 1,000.

1.4 Psychological Theories of ASD

Many psychological theories have attempted to explain the array of difficulties people with ASD present but the main ones, which are of significance to this research, are the theories of Weak Central Coherence, Theory of Mind, and Executive Dysfunction:

- ***Weak Central Coherence theory*** proposes that typically developing individuals process information in a holistic fashion, extracting the ‘general gist’, at the expense of details. This drive for global coherence is argued to be weaker for individuals on the Autistic Spectrum, leading them to process information in a detail-focussed and piecemeal way (Frith, 1989; Happé, 1999). Such a predisposition has implications for tasks requiring the integration of information and contextual considerations, including the interpretation of social situations
- ***‘Theory of Mind’*** refers to the ability to impute mental states, both to the self and others. This ability allows mental states to be represented in parallel, and at times in contradiction, to the physical situation; it enables both imaginative play and the prediction of others’ actions (Baron-Cohen, Leslie, & Frith, 1985). The Theory of Mind hypothesis proposes that individuals on the Autistic Spectrum experience

impairment in this ability, impeding their social understanding and capacity to navigate social situations

- The theory of **Executive Dysfunction** suggests that individuals on the Autistic Spectrum experience difficulties in their executive functioning and includes the skills of planning, impulse control and cognitive flexibility. The theory proposes that impairment in these skills is what causes individuals with ASDs to display a need for sameness, perseveration, and difficulties in switching attention and controlling impulses (Ozonoff & Strayer 1997). These difficulties are also argued to have detrimental effects on social skill developments

1.5 Use of term ASD/AS for Purposes of this Research

Although I do not subscribe to the perspective that Autism is a disorder, the term Autistic Spectrum Disorder (ASD) will be used to refer to all variations of Autism, as defined by the DSM V, except when using terms that come from earlier research. I have chosen to use Asperger Syndrome (AS) as the main term in the research study itself, as all of the participants were diagnosed with AS at the time of the study.

1.6 Context and Background of the Research Project

The guiding principle underpinning the research relates to what is considered to be in 'the best interests of the child'. This is a rights-centred approach to work with children enshrined in the United Nations Convention on the Rights of the Child (UNCRC), which was adopted unanimously by the General Assembly on the 20th November 1989 (United Nations (UN) 1990). The

approach demands that in all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

In the field of Autism an increase in the diagnosis of ASDs (Charman, 2002), combined with a drive for the social inclusion of all children with Special Educational Needs (SEN) (Department for Education and Employment, 1997; Department for Education and Skills, 2004b) has increased public and professional awareness and interest in ASDs.

Legislation surrounding ASD has increased in recent years. The Autism Act (2009) addresses the lack of local information about children and young people with ASD and the need for local agencies to include their needs in the planning of services, particularly during transition to adult services. Funding has been provided to ensure that the strategies are implemented at a regional level. Regulations and statutory guidance have also been provided to ensure that Local Authorities collect and share information about young people with ASD with a view to including their needs in Children and Young People's Plans, which in turn will ensure a multi-agency approach.

The Government's Green Paper *Every Child Matters* (DfES, 2003) proposed to address the way in which children's services operate. Central to the *Every Child Matters* vision was a more universal, preventative approach to working with children, together with a theme of early intervention rather than simply

targeted protection of identified vulnerable groups. The *Every Child Matters (ECM)* Green Paper set out a number of legislative commitments which were taken forward through the *Children's Act (2004)*; a report through which statutory guidance was provided for developing inter-agency co-operation in order to improve the well-being of children. The new Children and Family Act, which incorporates the advice on Special Educational Needs (SEN) legislation and the new SEN Code of Practice Guidelines (2014), advocates the importance of listening to children and parents.

It is the legislative commitment to eliciting the views of children that led me, the researcher, to consider how best to do this with those diagnosed with AS through qualitative research methods. My perspective was that, in order to access the voices of those with AS, there was a need to develop appropriate methods to ask, and not measure, what their views and experiences can tell us about how best to adjust the environment to ensure that it is more inclusive to their holistic needs.

1.7 Researcher's Position

I am a working class Afro-Caribbean black male from London who attended a comprehensive school and was the only person from my cultural background in this school to gain a place at University to study Psychology, where I became increasingly interested in the effects of the environment on young members of society, in particular the dilemmas that they faced in education. As a result of these studies and practical experiences, I decided to pursue a career as an Educational Psychologist.

I have a personal interest in ASD that stems from experience gained extensively in a variety of contexts and professional practices over 30 years in my capacity as a student, youth worker, teacher and special needs teacher, Educational Psychologist (EP), Specialist Senior EP and Consultant Specialist Psychologist. My employment has spanned a variety of settings including Education, Health, Social Care, Legal, Medical and Corporate. A breakthrough in my professional career came about when I had the opportunity to work with students in Further and Higher Education whereupon I became involved in working with adults with ASD.

In addition, I was extremely fortunate to have the opportunity to develop clinician assessment skills in ASD through being offered a consultancy post as part of a diagnostic team led by Dr Lorna Wing and Dr Judith Gould based at the Centre for Social and Communication Disorders in Bromley, Kent. Here, I was involved in the diagnosis of children, young people and adults with complex needs who had travelled from all over the country. I was also involved in the diagnosis and planning of provision in my LA as a Senior Specialist EP. It was through this work that I became interested in outcomes for children and families who had received a diagnosis of AS, in particular their experiences of obtaining a diagnosis and its impact on their education. A particular group identified were adolescent young men and their parents.

During this period of professional practice, I have developed ways of eliciting the views of the young person, often with parents (mostly mothers) present, and this has proved to be very powerful in completing professional

assessments. I acknowledged the importance of developing more understanding of how young people diagnosed with AS viewed their diagnosis and how this affected their lives, particularly their education.

1.8 Theoretical Basis to Research

This research has been guided by the following theories in constructing the research project:

Attachment Theory

Attachment theory in psychology originates with the seminal work of John Bowlby (1958) who worked as a psychiatrist in a Child Guidance Clinic in London, where he treated many emotionally disturbed children. This experience led Bowlby to consider the importance of the child's relationship with their mother in terms of their social, emotional and cognitive development. Specifically, it shaped his belief about the link between early infant separations with the mother and later maladjustment, and led Bowlby to formulate his attachment theory. Bowlby observed that children experienced intense distress when separated from their mothers. Even when such children were fed by other caregivers this did not diminish the child's anxiety. Bowlby defined attachment as a "lasting psychological connectedness between human beings" (1969, p.194). Bowlby (1958) proposed that attachment can be understood within an evolutionary context in that the caregiver provides safety and security for the infant. Attachment is adaptive as it enhances the infant's chance of survival. According to Bowlby infants have a universal need to seek close proximity with their caregiver when under stress or threatened.

This research aims to explore the nature of the relationship between mothers and sons to understand the bond between them.

Attribution Theory

Attribution theory deals with how the social perceiver uses information to arrive at causal explanations for events. It examines what information is gathered and how it is combined to form a causal judgment (Fiske, & Taylor, 1991). Attribution theory is concerned with how and why ordinary people explain events as they do. Heider (1958) believed that people are naive psychologists trying to make sense of the social world. He proposed that when we explain the behaviour of others we look for enduring internal attributions, such as personality traits. For example we attribute the behaviour of a person to their naivety or reliability or jealousy; further that when we try to explain our own behaviour we tend to make external attributions, such as situational or environment. This research aims to explore how the young men will explain their experiences of having a diagnosis of AS.

Positive Psychology

Positive psychology focuses on how to help human beings prosper and lead healthy, happy lives. Seligman, & Csikszentmihalyi, (2000) describe positive psychology as positive human functioning that achieves a scientific understanding and effective interventions to build thriving individuals, families and communities. Positive psychology can have a range of real-world applications in areas including education, therapy, self-help and workplace issues. Using strategies from positive psychology, teachers, coaches,

therapists, and employers can motivate others and help individuals understand and develop their personal strengths. This research lends itself to commenting on the positive experiences of the participants and, where possible, these will be highlighted.

1.9 Research Rationale

Until the Children Act (1989) was passed, legislation on the issue of child voice had limited existence. Following this, the Code of Practice (Department for Education, 1994) and the revised version (Department for Education and Employment, 2000) stated more clearly that children have a right to be heard and should be encouraged to take part in decision making. Billington, McNally and McNally (2000) proposed that the people themselves (children or their families) are the experts on their ASD and should be the collaborators in our future understanding of it.

There are clear moral, legal, educational and psychological arguments for listening to young people's views. There is some evidence that practice lags behind legislation. Tobias' (2009) article based on research in the UK begins with reference to the "Salamanca Statement" set out by UNESCO in 1994, which highlights the fundamental right to education of all children, whatever their needs or characteristics, and the principle of including children with special needs within mainstream schools. One study found that mainstream secondary pupils believe that consultation is 'tokenistic' and 75% of children with special needs reported not being consulted about moving into special education (Barrett and Dickenson, 2002). The difficulties inherent in seeking

the perspectives of young people with Special Educational Needs have been well documented (e.g. Armstrong, Galloway & Tomlinson, 1993; Davie, Upton & Varma, 1996; Milton, 2012). Notwithstanding any factors arising from the educational need itself, it has been suggested that young people's contribution "is often minimal" as a result of "difficulties in gaining access to children's thinking", and "constraints which influence the way professionals conceptualise children's needs" (Armstrong et al, op cit, p121). Accordingly, there is little literature on listening to young people with ASD, but clearly they should be consulted along with their parents.

Although much research has been undertaken establishing appropriate diagnostic criteria and interventions, little is known about the experiences of parents and children regarding having the diagnosis and on the impact of this on their lifestyles. As a specialist EP, I was keen to investigate this area in line with the new legislation recommending that children and young people need to be involved in any decision-making regarding their special educational needs.

Getting an understanding of young men and parents, experiences of a diagnosis of AS and its impact on educational outcomes is important for a variety of reasons. It is my view that professional practice needs to view parents as experts in terms of their child's needs. This is not a universal perspective and little has been written about young person's views of the diagnosis of AS and the impact of such on their education. Similarly little has

been written about young adolescent men diagnosed with AS', experiences of having the diagnosis and the impact of having this on their education.

1.10 Research Aims

One of the most important aims of this research was to gain the young men's (aged 13 to 19) views of the impact of having a diagnosis of AS on their education. This research is unique because, although much research has involved the views of adults with the condition, the views of young adolescent men have not figured. Indeed much of the work with young men has focused on assessing their needs in order to provide the correct interventions (Attwood, 2006; Baron-Cohen, 2008). In light of *Every Child Matters* (DfES, 2003), this research is intended to contribute to information on mothers and young men's experiences of obtaining a diagnosis of AS and the impact of such on their educational experiences. This will have implications for Children's Services and other professionals supporting young people with AS in developing an appreciation of their experiences of the diagnostic process and of the help and support available to them thereafter.

The research also aims to gain in-depth views of mothers and sons suggestions for future improvements. Whilst the focus will be on a small sample of parents and sons through exploration of their experiences, this research aims to contribute to identification of their needs for improved support and therefore contribute to a better provision of assistance for the young men throughout their life.

The relevance of this research lies in the increased number of adolescents being diagnosed with AS at a later age, resulting in a new population of parents and young people who need on-going support.

1.11 Contribution to Professional Practice

It is hoped that through gaining an in-depth understanding of some of the experiences of the parents and young men with AS, individual contextual factors might be identified to better understand their experiences and future. In terms of Educational Psychology practice as part of Children Services, it is hoped that this research will contribute to the focus on AS and perhaps highlight specific areas of need for further consideration. As the number of children diagnosed with ASDs continues to increase, this area of consideration should remain at the forefront of education and health professionals' minds. Of critical importance are views of young men's aspirations and transition to adulthood. Issues regarding mental health and well being; education and the social curricula; lifelong learning experiences and self-perception should remain at the forefront of professional thinking in order to support this complex and vulnerable group.

1.12 Distinctive Contribution

Huws and Jones (2009) acknowledge that, while there is a considerable volume of findings concerning parental experiences of (and reactions to) the sharing of a diagnosis, there appears to be little evidence concerning the experiences of the young people themselves. To date, it is my understanding that no study has specifically focused on the experiences of young adolescent

men with AS, of having a diagnosis of ASD and how this has impacted on their educational experiences. I was also interested in exploring parents experiences of gaining a diagnosis and what this journey meant in obtaining appropriate support to meet the young men's social, emotional and learning needs. This led to the overarching research question:

'How has the diagnosis of Asperger Syndrome impacted on the educational experiences of young men?'

2. LITERATURE REVIEW

2.1 Overview of Chapter

A literature review is a systematic, explicit and reproducible method for identifying, evaluating and interpreting the existing body of recorded work produced by researchers, scholars, and practitioners. (Fink, 1998, p.3)

In order to provide focus for a literature review, Gough (2007) highlights the importance of selecting a review question. To gain an overview of the body of research within which the current project will be situated, this review will aim to answer:

‘How has the diagnosis of Asperger Syndrome impacted on the educational experiences of young men?’

The main focus of this chapter is to complete a critical review of research about the impact of a diagnosis of AS on young men. It also reviews the impact of the diagnosis on the young men’s educational experiences, as seen from the perspectives of the young men themselves and their parents.

2.2 Introduction

In their article, Huws and Jones (2009) acknowledge that, while there is a considerable volume of findings concerning parental experiences of (and reactions to) the sharing of a diagnosis, there appears to be little evidence concerning the experiences of the young people themselves. What little

evidence there is indicates that reactions may vary widely. The sharing of the diagnosis may enable the person concerned to make sense of the difficulties or differences experienced, thus providing reassurance and increasing self-esteem. Alternatively, the reaction may be very negative and the disclosure perceived as psychologically and emotionally threatening.

This literature review is aimed to assist in progressing an understanding of the significance and importance of research on young mens views of having a diagnosis of AS and the impact on their educational experiences. The chapter provides an overall insight into ASD and AS and the evolving 'story' of understanding the diagnostic process, of gaining a diagnosis and the impact of this on families over time (based on studies from the USA and the UK). The issue of whether people on the Autistic Spectrum can be seen as just thinking 'differently', as opposed to the condition being seen as a disorder from the medical model, is also discussed.

A critical review of the research literature relating to the diagnosis of young men and the impact of such on their secondary educational experiences is presented.

2.3 What is Autism?

The term 'Autism' was first used by a psychiatrist called Bleuler in 1911 describing it as a form of 'childhood schizophrenia' (Bleuler, 1911 cited in Parnas, Bovet & Zahavi (2002). In the 1940's Kanner (1943) and Hans Asperger (1944) were, like Bleuler, studying small groups of children deemed

as having some form of 'childhood schizophrenia'. They all found that, with the groups of children with whom they were working, a set of distinct symptoms could be identified that remained markedly different from schizophrenia as it was conceived at the time. Kanner's work laid the foundation for early accounts of Autism, whilst the work of Asperger was left largely undiscovered until the 1970s.

Definitions of what Autism is, and also what caused an autistic developmental pattern in children, have been hotly contested ever since, including an unfortunate era where Autism was thought to be a reaction to 'refrigerator mother's, a theory long since shown to be totally untrue (Feinstein 2010; Kanner 1949; Rimland 1964; Wing 1974).

The guidance issued by the National Institute for Health and Care Excellence (NICE), a multidisciplinary body convened to provide guidance and recommendations to support those working with children with Autism (NICE-2011) defines Autism as: "Qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours, often with a lifelong impact."(p.16)

The NICE guidance further advises that, in addition, people with Autism frequently experience a range of cognitive, learning, language, medical, emotional and behavioural problems, including a need for routine, difficulty in understanding other people (including their intentions, feelings and

perspectives), sleeping and eating disturbances and mental health problems such as anxiety, depression, problems with attention, self-injurious behaviour and other challenging, sometimes aggressive behaviour. These features may substantially impact on the quality of life of the individual and their family or carer, leading to social vulnerability.

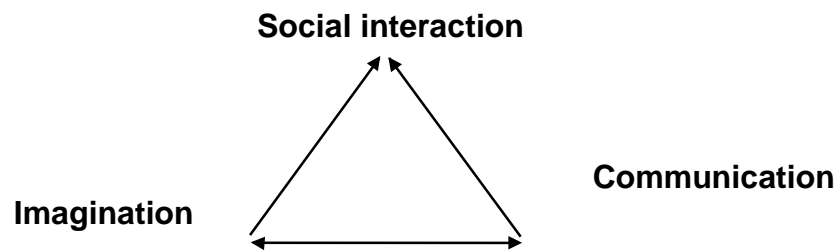
The NICE guidance recognises that the clinical picture of Autism is variable because of differences in the severity of Autism itself, the presence of co-existing conditions and levels of cognitive ability, from profound intellectual disability in some people to average or above average intelligence quotient (IQ) in others.

Finally, NICE advises that the way in which Autism is expressed will vary across different ages and therefore, for any individual may change over time as they mature in response to environmental demands, interventions and in the context of co-existing conditions.

2.3.1 Diagnosis and the Triad of Impairments

One of the most important developments in the history of Autism can be seen to be the work of Wing and Gould (1979) and the subsequent widening of the term Autism to 'Autism Spectrum' to include 'Asperger Syndrome'. This work largely created the contemporary definition of Autism as a 'Triad of Impairments' (NICE, 2011) in social communication, social interaction and imagination (repetitive interests/activities). Since this time, diagnostic systems have changed to reflect these changes in definition.

Figure 2.1: Triad of Impairments (Wing & Gould 1979)



The NAS defines Autism as a “Lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them” (NAS, 2012 p. 1). Such a definition of behavioural deficit and impairment has come to characterise both the International Statistical Classification of Diseases and Related Health Problems (ICD-10 – WHO 1992) and the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV, APA 1994) diagnostic criteria. The new DSM5 (American Psychiatric Association, 2013) has changed the criteria with regards to Autism which is referred to as Autism Spectrum Disorder (ASD) updating the confusion that had existed with regards to a number of other classifications such as Pervasive Developmental Disorder (PDD) and Asperger and the diagnostic criterion for AS are no longer seen to be distinct and has been omitted. The NICE (2011) standards are based on diagnostic criteria and as such promote a medical model of Autism that suggests that Autism is a disorder. However this can be seen as contentious, as is the DSM5, which omits AS. This research study will still use the term AS, as the participants were diagnosed prior to the DSM5 formulation.

2.3.2 Is Autism a Disorder?

Milton (2012), a researcher and autistic adult, argues with some conviction that how Autism is manifest can vary significantly between individuals and that this is socially mediated, via a process of constant interaction with changing environments. While problems with social and environmental aspects of the everyday world are common features of life for people on the spectrum, 'being autistic' should not be framed purely through a deficit model lens (Baron-Cohen, Ashwin, Ashwin, Tavassoli, & Chakrabarti, 2009; Gernsbacher, Dawson & Mottron, 2006; Milton, 2012). Indeed, there is evidence that people with Autism routinely outperform non-autistics in a range of perceptual, reasoning and comprehension tasks (Milton, 2012). However, these particular cognitive abilities appear less likely to be reported, or are reported as further evidence of deficit rather than an associated strength (Dawson, Soulières, Gernsbacher, Mottron, 2007; Gernsbacher et al., 2006).

Hacking (1999) frames Autism in terms of an interface between biology and culture, where factors relating to each domain are necessary but not sufficient to explain or even define observed differences between autistic and non-autistic people. Further, he argues that in Autism, biological factors appear to interact with classifications through social processes, giving rise to what he terms an 'interactive' phenomenon (Hacking, 1999).

In the current research, although the young men did receive a medical diagnosis, I wanted to explore the social and cultural context of their diagnosis

through an epistemological framework based on social constructivism (Willig, 2001), which will be covered in the next chapter.

2.3.3 Theoretical Perspectives to Challenge the Medical Model of Autism - Autism from the 'Inside-Out'

There are a number of psychological theories that have been put forward to describe Autism using a cognitive explanation, with some attempting to make links to biological and neurological data (e.g. Baron-Cohen, 2008; Happe 1994a; Happe 1994b). In order to produce cognitive models, all of them rely on accounts of behaviour to make inferences from. A major criticism of these models is that they are formed from a perspective of a bio-cognitive psychology overly restricted by its total adherence to scientific method as the gold standard, which does not value the input of 'autistic voices', or that of psycho-sociological viewpoints on Autism. This seems to have come about for a number of reasons, one of which being evidence based research for biomedical explanations earned at the expense of previous theories such as Bettelheim's (1967) theory of the 'refrigerator mother'.

The pure medical model doesn't allow the inclusion of culture and context. What is more, in recent years, the autistic adult community has provided more reflections on these issues (e.g. Milton, 2012). These changes in understanding Autism over the years, particularly in the West, have impacted on the autistic community and their families. For example the mother is no longer seen as the cause of her son's condition and that the blame lay at the neurology of the 'autistic person'. Milton (2012) contends that all the

psychological theories of Autism base their models within this criterion of behaviour led framework although, in the Monotropism theory (Murray, Lesser & Lawson, 2005), this is balanced by the accounts of lived experience of 'autistic people' themselves. Monotropism, a typical feature of Autism, is when an individual has a restricted range of interests and can only pay attention to what is in his/her attention tunnel. Monotropic individuals tend to become too focused on a certain object or activity and find difficulty in shifting their attention, whereas a Polytopic individual is capable of spreading his/her attention to multiple things at one time. Monotropic individuals often display stereotypes, which occur because the individual focuses his/her attention on one thing and repeats it until the attention moves. It is also related to monoprocessing, which is defined as the ability to only process information from one source at a time. This is a way to cope with their hypersensitivity to sensory information. Milton goes on to state that the current psychological models seem somewhat inadequate at drawing the links between biology and behaviour but, even more so, between biology and the lived experience of autistic subjectivity, often attempting to obscure the 'autistic voice' or ignore it, in an attempt to reduce autistic behaviours to definable objective criteria. The next section continues the view that people with Autism need to be heard and actively involved in research about them.

2.4 Involving People on the Autistic Spectrum in Research as Active Partners

Talking about Autism was, for many years, the exclusive preserve of clinicians and researchers where autistic people were objects of inspection, rather than

active participants in the creation of knowledge relating to their own experiences (Feinstein, 2010). Williams, (1996) illustrates this point:

“...right from the start, from the time someone came up with the word ‘Autism’, the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced.” (p.14)

While the emergence of self-advocacy movements and the entrance of academically trained autistic researchers into knowledge production has begun to challenge these conditions (Arnold, 2010; Dawson et al., 2007; Graby, 2012; Milton, 2012; Murray, Lesser & Lawson, 2005), these tend to be the exception. Obtaining the views of disabled people is now a requirement of policy legislation, both nationally and internationally (Pellicano & Stears, 2011; U.N., 2006).

Milton (2012) advocates that research in Autism needs to include autistic voices within knowledge production through research that engages with lived experiences. Milton & Bracher (2013), in their paper ‘Autistics speak but are they heard?’ state that in order for there to be a significant shift in the research agenda, the silencing of autistic voices and tokenistic practices must be replaced by meaningful involvement of autistic people in understanding Autism – including (but not limited to) the employment of appropriately trained autistic people in research teams. With such involvement, the research agenda would be broadened, rapport with research participants might improve, dissemination of findings would be less offensive to the autistic community and autistic people would be less alienated from knowledge

produced in the field. Crucially, such developments would increase the epistemological integrity of studies that seek to explore important questions relating to the wellbeing of autistic people. The current study was developed to gain more insight into the views of young men with AS and as Ne'eman, (2011) points out:

"We have to challenge these myths and stereotypes about Autism and work to advance an understanding that is based on better quality research, but also on the real life experiences of those of us on the Autism Spectrum rather than a conversation that talks about us, without us. By taking that step together, we will see more progress for self-advocates, providers and families." (Ne'eman (2011) Question and Answer interview, accessed at <http://www.talkaboutautism.org.uk/community/live-qa-events/010611-ari-neeman>, on 01/07/2014.)

The new Children and Family Act, which incorporated the advice on Special Educational Needs legislation and the new SEN Code of Practice Guidelines (2014), advocates the importance of listening to children and parents. It is clear from the preceding sections that it is critical to elicit the views of those diagnosed with AS through qualitative research methods. If we are to access their voices we need to ask, and not measure, in order to determine what their view is and what their experiences can tell us about how best to adjust the environment to ensure that it is more inclusive to the needs of those with AS. The following strands will be reviewed in order to summarise the relevant literature:

2.5 The Development of the Literature Search

As discussed in Chapter 1, my professional experiences led to the investigation of this particular topic area. The aim of the research study is to develop a greater understanding of young men diagnosed with AS, their experiences of having the condition and their thoughts about its impact on their education.

The formal review of the literature commenced at an early stage in the formation of the research. This was carried out to develop an overall understanding of the subject area and to locate the seminal research. A further review of the literature was completed more recently following the analysis of the research findings in order to update and review the research questions that were developed. Silverman (2005) advises that a literature review needs to be completed following the analysis of the research and that this will assist in making sense of the data.

Over a period of time a number of databases were researched including those in EBSCO and internet search engines using several different terms in an effort to obtain a wide range of information from research papers, articles, scholarly books, fictional literature and pages from the World Wide Web. More recently an update of relevant studies was systematically searched for on a number of online databases including PsycINFO, Education Research Complete, Science Direct, Academic Search Complete, The Article First, British Library Serials, ERIC, JSTOR, Medline, Psycho-Info, Web of Science and NEXIS for newspaper articles. Some articles were found through 'word -

of-mouth', hand searches and reading the reference sources of articles covering the subject matter in professional journals such as the Journal of Child and Educational Psychology and Educational Psychology in Practice. Finally, the National Autistic Society's (NAS) Library proved to be an extremely useful resource.

In order to identify relevant research studies, the search inclusion criteria involved combining the following keywords:

- Diagnosis of Autism Spectrum Disorders (ASD) and Asperger Syndrome (AS).
- Asperger Syndrome (AS) and parents.
- Mothers of children with ASD, AS.
- Asperger(s), high-functioning Autism, ASD.
- Adolescence, adolescent.
- Experiences, self-concept or self-perception.
- Views or opinions.
- Education, mainstream, inclusion.
- Peer, friendship, social.
- Intervention(s), support.
- Young men, young people.

Studies included in the review met the following criteria:

- (a) Participants were aged between 10 and 19-years-old; and
- (b) Participants had a diagnosis of AS or were referred to as AS/high-functioning Autism

- (c) A time period spanning 10 years (from 2004 to 2014) – although seminal works were considered if they were published earlier.

Many of the seminal papers assisted in providing links to other relevant research including at an international level. It was noteworthy that it took much time and effort to access up-to-date research from countries other than the UK, often included in journals not subscribed to by UK libraries. The process of selecting the studies for the literature review involved talking to peer professionals who had carried out similar research in the field. I was able to gain some invaluable insights from attending an interest group which focused on qualitative research and this enabled me to consider my own viewpoint as to how to approach the literature review which was a continuous process taking place prior to and following the analysis of the study. Throughout this process I was able to draw on the objective advice offered by my research supervisor and external consultant. On completion of this process, 62 papers were identified. Each was read for relevance and quality; those that were deemed highly relevant to the review question and demonstrated validity, reliability and/or trustworthiness were selected for the literature review. Based upon these judgments, 42 empirical studies that drew upon a range of epistemological and methodological approaches were selected (see Appendix 18). From the literature search it became apparent that there were a variety of facets to explore in terms of the diagnosis of the young men with AS and educational outcomes. It was decided that it would be important to critically review 15 studies (Appendix 19) identified from the following strands:

- Parents' experiences of the journey to obtain a diagnosis of AS for their son.
- Parents' experiences of their son's secondary education following the diagnosis.
- Young men's experiences of secondary education following the diagnosis.
- Young men's experiences of having a diagnosis of AS.

These strands are presented sequentially, within which each paper is critically discussed. Finally, it is demonstrated how the review assisted in developing the conceptual framework, theoretical underpinnings and methodology for the research study.

I am mindful that findings from these studies are set in one country, with its particular culture and social norms, organisation of mental, physical and developmental services, ethnic and racial groupings and do not necessarily generalise in full to the situation in another country. It is likely that there will be at least a considerable degree of shared significance and implications, but there needs to be some caution before assuming transferability, generalisation and equality of potential impact upon policies and practices.

The debate regarding the terminology, diagnosis, theoretical and psychological perspectives that challenge the notion that Autism is a disorder is outlined below.

2.6 Strand 1: Parents' Experiences of their Journey to Obtain a Diagnosis of Asperger Syndrome for their Son

One of the first studies to highlight difficulties experienced by parents to get a diagnosis of Autism was carried out in 1987 by Howlin and Moore in which 1300 parent members of Autistic Societies in the UK were interviewed regarding the diagnostic process. From a detailed survey, data was collected on the age at which the diagnosis was made, time taken to obtain the diagnosis and the professionals involved. Differences in geographical areas were also assessed. The findings indicated that, although children were being diagnosed earlier than in previous decades, the average age was around six years. It was found that wide regional variation existed and many parents continued to experience lengthy delays before they received a diagnosis. The authors found that parental satisfaction was much higher when children were diagnosed early (between ages 0 to 5 years), than those diagnosed much later and practical support was considered to be of high importance once the diagnosis was made. The report recommended the development of early year's provision to help children with Autism develop skills and strategies that could be utilised throughout their lives in order to reduce later incidences of more challenging behaviour.

In this strand the research on parents' experiences of their journey will be reviewed.

2.6.1 Parental Experiences during the Diagnostic Process

A study by Sansostini, Lavik and Sansostini (2012) in the USA set out to research parental experiences during the diagnostic process including factors influencing the time taken and parental perceptions of the available intervention services. Participants were parents of 16 children, aged up to 7 years, who had been diagnosed with Autism.

The findings indicated that the parent's first concerns and observable indications of their children presenting with some 'difference' arose between 12-24 months. The mean age at which concern was shared with a paediatrician was 24-36 months and the mean age a diagnosis was made was 48 months. Interestingly, children with a more severe form of autistic-like behaviour/symptoms were not diagnosed more quickly; maternal education and family income were unrelated to the time taken to reach a diagnosis. The parents provided accounts of their qualitative experiences during the diagnostic process, which included:

- A lack of up-to-date information about Autism on the part of doctors/teachers.
- An 'overwhelming' sense of uncertainty following the diagnosis.
- Being left to find information about Autism for themselves and about possible courses of action.
- Professionals who did not appreciate or share the parental concerns and seemed unwilling to take account of parental information.

- Encountering some opposition from teachers/professionals in the education service in identifying and implementing appropriate provision.
- Having to fight for any provisions due to a lack of cooperation/collaboration by teachers/administrators.

It was commonly reported that the diagnosis significantly changed the parents' lives in the following ways:

- Giving up jobs/career possibilities to look after the children.
- Most friendships were with the families of other children with Autism.
- Day-to-day routines being shifted to fit to the children's needs and their varying behavioural/emotional states.
- Ceasing going out on recreational visits due to anxieties about the likely reactions of other people to the children's behaviour.
- Increased stress along with some impairment in the parental relationships.
- Financial pressures.

However, the authors point out that a number of parents said that their families were able to adjust and settle into a routine and new ways of working with their children with Autism. Most parents reported being satisfied with the information received from professionals with specialist training and experience in Autism once they had managed to meet them.

The authors acknowledged the limitations of the study in terms of the small number of participants and their volunteer status (perhaps including parents who had a particular 'axe to grind'). They argued it is critical that early concerns expressed by parents are taken seriously and information from all available sources and well-validated assessment measures is gathered in order to fully explore the at-risk status of the child. It is also worthy to note that this was a sample in one particular area of the USA and another part of the country may have yielded very different findings.

In the next section the impact of having the diagnosis on the parents is considered.

2.6.2 Impact of Diagnosis on Parents' Role

Stoner & Stoner (2014) carried out semi-structured interviews investigating the impact of a diagnosis of Autism on the parents' role. This research highlights the experiences commonly experienced by parents and included participants comprising eight sets of professional parents of children with ASD attending various grades of schooling across a number of districts in the USA with face to face interviews using broad and open-ended questions.

The authors highlighted the following:

- The potentially profound effects of the necessary changes to lives and routines as a result of providing care to a child with Autism.
- Some parents became heavily involved in exploring the various educational, psychological or physical needs of the children.

- Parents generally found support from their partners, other members of the extended family and from parent groups.

The authors commented that service providers need to be sensitive to the likely significance and impact of a diagnosis of ASD for the parents. There are not just practical and financial needs and issues, but socio-emotional reactions, coupled with some loss of valued social interactions when relationships and social contacts would have been especially important. The period prior to, and immediately after, the identification of the ASD (when parents are striving to understand the implications and to identify available services) is likely to be especially challenging and marked by anxieties and some sense of isolation.

It was acknowledged that the study was limited by the small size of the sample of participants, its recruitment from one region of a mid-western state of the USA that all the parents had a high level of education and had been career-orientated and could be said to represent a fairly narrow and advantaged segment of the community. The authors recognised the need for further surveys to attempt to reflect the full range of parental circumstances and experiences, the nature and severity of child symptoms across the full spectrum and varying access to formal and informal support.

A significant issue noted has been the quest by parents to normalise the diagnosis to ensure that their child is not discriminated against by society's

norms and access to equal opportunities. The following study explores this issue in more detail.

2.6.3 Parents and Normalisation (Normalcy)

Lasser & Corley (2008) argue that the particular circumstances of parents of children with AS have not been extensively explored and their work set out to identify the challenges faced by such parents, their ways of dealing with the challenges and the meaning they drew from their experiences. Their grounded theory study involved interviewing 20 parents (19 mothers and one father) whose children were reported to have a diagnosis of AS in the UK.

Participants also completed a background questionnaire (demographic information and relevant family history). A range of initial themes emerged:

- ‘Constructing normalcy’, which refers to attempts by parents to create some meaning out of their circumstances and to establish the best environments and arrangements for adaptive outcomes in the children.
- Children with AS appear ‘entirely normal’ to other people so problem behaviour is unexpected and probably regarded as deviant or the result of parental deficiencies.
- Normalcy was approached via comparisons of the children with AS against siblings or other children and by obtaining a formal diagnosis and advice as the first step towards mobilising appropriate resources.

The authors accepted that the sample size was small and composed of volunteers, so cannot assume that the responses are representative of the whole population of parents of children with AS. Nevertheless, they hold that a

significant finding of this study concerned the means of managing a disability with variable visibility, which may underlie, at least to some extent, the observed variation in the stress levels experienced by parents. Stress may arise when 'critical moments' are anticipated, such as when the children attend new settings or meet other people who are not aware of the AS and who may, therefore, be critical of any apparently challenging or odd behaviour on the part of the child.

The next section focuses on the mother's role as advocates for their child diagnosed with an ASD.

2.6.4 Maternal Experience (Advocacy and Activism)

In the introduction to their review of relevant findings and their own survey of parents conducted in the UK, Ryan & Runswick-Cole (2009) hold that the role of advocate on behalf of their children is one that many parents will adopt. Thirty six parents were interviewed involving a general and open-ended question seeking their comments about the experience of providing for the son or daughter with an ASD, followed by a set of questions designed to gain information about the impact upon the parents themselves, involvement with support groups and the nature of interactions with professionals. The parents were recruited from support groups, LEA parent coordinators, newsletters and on-line communications. The goal was to ensure a range of ages, social class, geographical location, level of disability of the autistic child and size of family. The data was analysed through a thematic approach and the findings indicated:

- Parenting children who require more than ‘normal care’ included maintaining protectiveness over a prolonged period.
- Having to fight on behalf of the child enabling them to be part of community events and facilitating the children’s interactions with other children.
- Increased opportunities as the mothers became involved as advocates or activists (joining forces with other parents of children with ASD via support groups).

Limitations to this study and indeed all of the qualitative studies reviewed rest in the small sample size. Nonetheless the findings are replicated in the previous studies reviewed regarding impact on parenting (mothers), a fight to ensure the child’s rights were recognised and financial constraints following diagnosis.

In the final section parents’ experiences of the services offered as a result of this is reviewed.

2.6.5 Parental Experiences of Services for Children with Disabilities

In their article Robert, Leblanc & Boyer (2014) comment that parents of children with developmental disabilities are more vulnerable to stress and a sense of adversity than other parents. This interview study was designed to investigate parents’ direct experiences of specialist support services and was set in Quebec, Canada where parents were recruited by a group of

professionals involved in support services for children. The parents included seven with at least one child with an ASD and eight with at least one child with an intellectual disability (14 mothers and one father). The focus was on parental experiences with specialist services which could be labelled as positive or negative, with emphasis upon parental experience at the time of receiving the diagnosis of a disability and involvement with support services. Positive experiences included the receipt of essential and practical information concerning the child's needs (to understand what the child is experiencing, improve communications and provide some guidance concerning the management of challenging behaviour). However, negative experiences occurred when there were changes in support staff. In addition a lack of coordination among services, delay between receiving the diagnosis and the availability of support, access to more assessments and the matching of additional diagnostic criteria) and the failure by professionals to adequately recognise parents' knowledge and experience also produced negative experiences.

The authors discussed the issue of who is to be seen as an expert. Parents who were largely satisfied tended to view support professionals as having specialist expertise and consequently did not challenge the nature of the support provided. Parents expressing more negative feelings argued that they were expertly knowledgeable about their own child and should have a greater say in decision-making. Among parents expressing general satisfaction, the main goals were:

- Improvement of daily life and interactions with the child.

- Maintenance of a good family atmosphere.

Those less satisfied were more likely to:

- Believe that specialist services existed to accelerate the child's progress across a range of domains and to take advantage of the child's ability to learn and to progress generally, despite the disabilities.
- Fight for what they considered was necessary for the child to achieve his/her full potential.

The authors highlighted the significance of involving parents fully in initial decisions about approaches to support services and about ongoing interventions in order to demonstrate recognition of the parental knowledge and potential contributions. The authors argued that effective support should be a matter of matching the intervention in line with parental views of the child's needs and the way in which the needs should be addressed. Parents were likely to be the most effective advocates for the children and, therefore, it is right their views are seen as an important aspect of the basis for planning. The authors acknowledged that their study was limited by the small size of the sample and by its recruitment from only one region. Despite this they felt it legitimate to conclude parents of children with disabilities were more vulnerable to stress and their well-being and satisfaction with services appeared to depend on the responsiveness of the system, its sensitivity to the particular circumstances and the idiosyncratic needs of the child and family.

In Strand 2 the experiences of accessing appropriate educational support are considered from the parental viewpoint.

2.7 Strand 2: Parents Experiences of their Son's Secondary Education Following the Diagnosis

Strand 1 highlighted the parents' experiences of obtaining a diagnosis of AS and its impact on parental stress and well being. Central to this has been the advocacy/activist role that parents, particularly mothers, have had to adopt to ensure that the diagnosis was made in the best interests of their children. This next strand investigates the experiences of educational outcomes for parents of young people diagnosed with ASD, including AS. Areas covered include parental experiences of transition to mainstream secondary school, views on education provision, experience of young people with ASD (as reported by parents) and what constitutes good inclusive practice.

2.7.1 Parental Experiences of the Transition to Mainstream Secondary School

Tobin, Staunton, Mandy, Skuse, Hellriegel, Baykaner, Anderson & Murin (2012), conducted a qualitative examination of parental experiences of the transition to mainstream secondary school for children with ASD. Participants were recruited through advertisements placed on relevant websites such as that of the NAS. The objectives of the study were to identify parents' hopes and concerns regarding transition, problems encountered and how they coped with it. The study used focus groups (prior to transition to secondary school) and follow up telephone interviews (18 months following transition) to gather

data. Seven parents participated in the study (five mothers, two fathers). The findings were analysed through thematic analysis (Taylor & Bogdan, 1984) in which parents reported that:

- Schools did not begin the transition process early enough.
- Transition should be individually tailored.
- Many mainstream schools lack the resources/staff training required to accommodate the needs of their child.
- Poor communication often stemmed from a lack of understanding of ASD.
- Good communication was underpinned by understanding, preparation and acceptance of the resource limitations.

Anxiety arose from two aspects of the transition process; that their child would be unhappy at their new school and transition would not be smooth. Other concerns included bullying and homework. Parents identified with that of being a fighter/pushy parent, believing they were viewed as forceful, but felt this was the only way to be heard when communicating with school personnel.

The authors concluded that, for some of the parents, successful inclusion in mainstream education was unrealistic. Even in cases where the transition was a moderate success, parental experiences of school selection, statutory assessment and preparation for the move proved highly stressful and anxiety provoking.

An implication from these findings was that parents would benefit from individualised support and transition planning. Specialist provision in a mainstream environment, such as ASD units, was seen to be a preferable option for parents. The study found that preparation, communication and coping skills were core to the parents' experience of their children's transition. The authors suggest that future research should survey children's and parents' attitudes towards such units and evaluate their effectiveness. They recommend that provision of specialist ASD training for education staff and improved communication between school and parents when managing transition is an important preventative measure against future difficulties for children with ASD. The authors advocate that professionals, such as educational psychologists, should work with schools and support parents to alleviate anxiety during this stressful time.

Limitations of their study were acknowledged by the authors through recognising that the findings reflected the perceptions and experiences of a small number of volunteers recruited through Autism support organisations, that there may have been a self-selection bias favouring parents who were encountering problems and fathers of children with ASD were under represented. Nonetheless the research incorporated a different approach to gathering data from parents in the form of focus groups and telephone interviews.

In the next section the views of parents' satisfaction regarding mainstream inclusion is considered.

2.7.2 Children with ASD in Mainstream Schools: Parental Perceptions

Whitaker's (2007) research was designed to investigate parents' experiences and perspectives regarding educational provision, with some exploration of the factors underlying varying levels of satisfaction. Questionnaires were sent to 172 parents in the UK whose children had ASD and were being educated within mainstream classroom settings rather than in specialist units attached to mainstream schools. Of the 172 parents, just over 60% described themselves as satisfied or very satisfied with the provision. This was seen as encouraging, but a number of provisos were set out:

- The number of parents expressing dissatisfaction - nearly 40%, a substantial minority.
- Some of the parents who reported satisfaction still identified issues of significant concern.
- Parental expression of satisfaction did not guarantee that the child's needs were being addressed appropriately.

Parents also identified issues they considered priorities for this satisfaction including the young person's progress in social skills, level of understanding among the staff of individual needs, capacity of staff to manage behaviour, the level of structure available and the child's happiness in the school setting.

Whitaker highlighted a number of parents' shared aspirations and wishes for their children, namely:

- Access to a setting where the needs and characteristics associated with ASD are understood by school staff and use of appropriate teaching and management strategies.
- Positive peer interactions and the promotion of relationships and social skills.

Unstructured breaks and lunchtimes were a particular source of problems, including bullying. Some parents argued that schools should be more proactive in promoting peer awareness and acceptance of children diagnosed with ASD.

In respect of home-school relationships, the two sub-groups of parents could again be clearly differentiated in that the quality of the communication was linked to the overall satisfaction expressed. Where satisfaction was high, parents frequently made specific references to good communication with staff involving a willingness to listen to parental concerns and to tap into parental knowledge and experience when seeking to deal effectively with issues arising at school. Among parents generally dissatisfied, communication was commonly a source of concern. Finally, Whitaker highlighted that the heterogeneity of children identified with ASD in mainstream schools must be recognised when educational provision is planned or reviewed.

The limitations of this research included not as much qualitative information generated from a large sample size. It would have been interesting to follow up through qualitative interviews, some of the issues alluded to in the survey

such as communication and parents' low expectations of staff awareness of Autism and appropriate teaching strategies.

A crucial point made in Whitaker's study addresses the children's vulnerability in managing the social issues of school life. The next section addresses parents' views on how inclusive practices can help to foster their children's emotional well-being throughout their education in mainstream schools.

2.7.3 What Constitutes Effective Inclusion in Mainstream Secondary Schools for Pupils with ASD?

Alexander, Franks, Gardner, March, Paterson, Scott & Smith (2005) investigated what constituted effective inclusion in secondary schools through exploration of the mainstream provision made for pupils with ASD. One quarter of the LEAs in Scotland were selected randomly to participate in the study, which involved questionnaires being sent to all secondary schools in the selected Authorities seeking their views. The questionnaire items were designed to reflect the guidance given in "Creating an Autism Friendly Environment" (Smith and Brown 2000). Respondents were asked to rate the extent to which they felt their school practiced each of the items on a five-point scale. From the overall returns, six schools were selected which rated themselves as "strongly agreeing" that their school did indeed practice successful inclusion of pupils with ASD. The Education Officers and Head Teachers of these schools were approached by telephone and letter, in order to seek their agreement for a more in depth research into their schools' practice. The final stage involved groups of researchers visiting the schools

identified for a day and conducting semi-structured interviews with 12 sets of parents, staff and 24 pupils to determine more fully their views about what constitutes good practice in inclusive education.

For the purpose of this strand the focus is on the findings from the parents' interview (addressing the findings of the pupils will occur in Strand 3). In this study, two sets of parents in each of the six schools were asked their opinions on the experiences they and their children had throughout their school years. The interview responses were felt to reflect parental views of what constituted effective provision for their children and whether inclusion worked for them. A number of key areas were discussed including:

- Diagnosis.
- Support.
- Curriculum.
- Partnership with school.
- Children's involvement.
- Social/life skills training.
- Bullying.
- Family issues.
- Suggested improvements.

The main themes appeared to be of both an emotional and practical nature.

In the majority of cases parents felt:

- Schools tended to offer a flexible curriculum covering a variety of provision (from full-time in a specialist base to inclusion within

mainstream), adjusted according to the pupils' needs. There was evidence of two schools using outside agencies to teach social skills (one using a local independent school, the other a charity).

- A two-way flow of information was very supportive (daily diaries, planners, regular meetings, personal contact, phone calls, letters, parent's nights, reports).
- A link person in school was beneficial (this person knew the child very well).
- Everyone was moving in the same direction and they were involved in the day-to-day issues regarding their child's education.

In contrast, there were some issues raised where parents felt that there was not enough discussion with the young people about their diagnosis and the problems that it produced for them as teenagers and that, although most schools offered training in social and life skills, peer buddies helped the young persons to acquire these skills more naturally. With regard to improvements some parents felt that peers and parents of their children's classmates should be educated about the nature of the difficulties and that good transition arrangements were essential to allow their children to move up from primary.

Limitations of this comprehensive study are hard to determine but one might suggest that it was linked to a country where the emphasis on inclusion and resources to facilitate was likely to have impacted the findings. It was noticeable that the study focused on schools identified as displaying good

inclusive practice towards promoting positive learning experiences for children with ASD in the mainstream secondary school environment.

Strand 3 incorporates young people's views of educational outcomes following a diagnosis of Autism.

2.8 Strand 3: Young Men's Experiences of Secondary Education Following the Diagnosis

When seeking to examine an individual's lived experience in an effort to increase understanding and inform support, perhaps the individuals themselves, as noted by Speraw (2009) are, "the most expert, most capable of telling what it is like to be them, living in their bodies, requiring assistance or accommodation, often on the margins of childhood or young adulthood" (p.736). Perhaps the best mechanism to ensure that this voice is not overshadowed is to present it without any competing adult perspectives. Until the Children Act (1989) was passed, legislation on the issue of child voice had limited existence. Following this, the Code of Practice (Department for Education, 1994) and the revised version (Department for Education and Employment, 2000) stated more clearly that children have a right to be heard and should be encouraged to take part in decision making. Billington, McNally and McNally (2000) proposed that the people themselves (children or their families) are the experts on their Autism and should be the collaborators in our future understanding of it.

There are clear moral, legal, educational and psychological arguments for listening to young people's views. There is some evidence that practice lags behind legislation. Tobias' (2009) article based on research in the UK begins with reference to the "Salamanca Statement" set out by UNESCO in 1994, which highlights the fundamental right to education of all children, whatever their needs or characteristics, and the principle of including children with special needs within mainstream schools. One study found that mainstream secondary pupils believe that consultation is 'tokenistic' and 75% of children with special needs reported not being consulted about moving into special education (Barrett and Dickenson, 2002). The difficulties inherent in seeking the perspectives of young people with special educational needs have been well documented (e.g. Armstrong, Galloway & Tomlinson, 1993; Davie, Upton & Varma, 1996). Notwithstanding any factors arising from the educational need itself, it has been suggested that young people's contribution is often minimal" as a result of "difficulties in gaining access to children's thinking", and "constraints which influence the way professionals conceptualise children's needs" (Armstrong et al, op cit, p.121). Accordingly, there is little literature on listening to young people with ASD, but clearly they should be consulted along with their parents.

Strand 3 focuses on young men's experiences of secondary education following the diagnosis of ASD/AS. Some of the studies reviewed include the views of parents and young women but the main focus was to identify what the young men are experiencing in their secondary education following diagnosis.

2.8.1 Experiences of Secondary School Education

A study by Hill (2014) was conducted in a Local Authority in the south of England, investigating the experiences of secondary school education from the perspective of young people with a diagnosis of ASD. Whilst the majority of young people diagnosed appeared to be achieving well against objective measures (attainment data, attendance figures and exclusion data), little was known of the broader, social and affective experiences of these young people. The author points out that this concern is also reflected in the research literature where there is a dearth of research focusing on the experiences of young people with ASD (Jones & Frederickson, 2010).

Hill's innovative study's main aim was to provide the participants with tools that would enable them to set the agenda for discussion and to take an active researcher's role. Interpretative Phenomenological Analysis (IPA) was adopted allowing for representation of different realities, whilst also searching for shared themes. Data for this research was collected via photo elicitation discussions. Participants were tasked with taking photographs of places in school that were of particular importance to them, these subsequently being used as the basis of informal discussions led by the young people. Such an approach removed concerns regarding researcher bias, with the young people making decisions on the images to capture and discuss (Zambon, 2005). Using photographs as the focus of discussion took away the pressure from the young people as the central point of attention (Carlsson, 2001). Students met with the researcher on four separate occasions, with one week separating each of the meetings. Six young people (males and females) from two

different secondary school settings took part. Three themes emerged from the analysis including 'anxiety', 'sanctuary' and 'young people as active agents':

- *Anxiety* – Each were found to have particular areas in which they experienced anxiety or stress within the school environment. For one student corridors were a huge source of anxiety, another was exams (with some students finding the exam setting very distracting). Daily 'meet and greet' sessions to express any concerns with a trusted adult were found to be helpful. Teaching Assistants were seen as a source of guidance when problems were encountered, or when schoolwork was too difficult.
- *Sanctuary* - the support *base* was identified as an area providing a 'calm and relaxing' environment to spend breaks and lunchtimes. Predominantly, the young people appreciated the security of the space itself, rather than the activities that were on offer.
- *Young People as Active Agents* - In this study the young people showed an interest in their mainstream peers. Several went to great lengths to make themselves aware of the activities in which these peers engaged, including watching and learning from their behaviour so as not to be seen as different. Students spoke of their long-term career aspirations, these being well matched to their areas of special interest, and appeared to have enthusiasm and optimism regarding their future educational experiences.

The author highlights the research to add weight to the idea that, whilst a group of people may share a common diagnosis, their needs may not be the

same (Lewis & Kellet, 2004). She further comments that there was considerable variation within the identified themes including: how the same event was experienced by different individuals, triggers for a shared feeling, individual requirements in terms of levels of desired social contact with typically developing peers and a variety of participation wishes.

Crucially this research has highlighted that, whilst it is of importance to look through an ASD lens, it is of greater importance to focus on the unique strengths, needs and interests of the individual young person. The importance of involving young people in the planning of provision to meet their needs is emphasised as they showed themselves to be insightful and competent in reflecting on what they found helpful and what could further enhance their education. The use of photographs had greatly facilitated the young people's ability to discuss their experiences in more detail. The author highlights the possibilities for not only the research community, but also for those involved in gaining the voice of young people with social and communication difficulties for a myriad of purposes (including school review meetings and person-centred planning).

The next section focuses on young people's views on support provided to them.

2.8.2 Views on Support

The aim of Tobias's study (2009) was to examine the views of students with Autism and parents about support available in secondary schools and to

determine what has proven most helpful and what additional support could be offered. The student groups comprised seven Year 9 and three Year 11 participants (male and females) in a mixed secondary school. The parent group comprised five volunteer parents. Using focus groups, the students were asked to describe their perceptions of students who were considered successful and unsuccessful. The questions built on Personal Construct Theory with a view to determining how the students regarded and made sense of themselves in the context of the school. They were also asked to suggest resources that might assist in supporting them in the school day. With regard to aspects of current support seen as helpful, references were made to targeted support at significant transition points including:

- Communication between staff and parents to deal with concerns and anxieties as soon as they were evident.
- Individually planned support to match particular profiles of types and levels of needs among the students.
- Staff commitment to the students, to the principle of inclusion and consistency in approach.

Suggestions about where and how support might be improved included:

- Increasing self-awareness by providing students with a greater understanding of ASD.
- Fostering a sense of belonging and inclusion to limit the probability and anticipation of bullying and to increase participation in social groupings.
- Fostering independence by increasing the efficiency of self-organisation and coping mechanisms.

- Developing life skills, including direct teaching of social and life skills that will be critical in the post-school world.

In her discussion the author described a logical next step as sharing the views expressed with the staff and other students and the gathering of their perspectives. This would help to determine how specific these current views are and a useful follow-up would be to repeat the focus group exercise with similar students and their parents in future Years 9 and 11 to observe whether any changes in policy and practice have been implemented and found to be effective.

Whilst it is acknowledged that this study was small scale, it is argued that the key themes and conclusions about support are of significance, notably in respect of seeking to fit the provisions to the needs of the student rather than seeking to change or 'normalise' the students in order that they can somehow 'catch up' and be fitted to the existing and unmodified school arrangements. Communication between staff and parents is highlighted as significant in determining appropriate goals and areas for ongoing attention, along with a monitoring of the student's own reported experiences, concerns, successes and aspirations.

The final section in this strand focuses on young people with ASD/AS experiences of secondary mainstream inclusion.

2.8.3 Effective Inclusion in Mainstream Secondary Schools for Pupils with ASD

Alexander et al's (2005) comprehensive study (see strand 2.7.3 for background information) involved eliciting young people's views about what made their school an effective or 'good' experience for them. Part of this research used particular techniques drawn from personal construct psychology (e.g. Kelly, 1955) and solution-focused approaches (e.g. de Shazer, 1994). Both these approaches are designed to help individuals elaborate and reflect on their responses, drawing information from their own experiences with a minimal level of constraint imposed by the person asking the questions. In this study, the aim was to elicit information that would reveal surface and higher-order constructs and so determine the principles of what would make a good inclusive school from the pupils' perspectives. The use of higher-order construct elicitation techniques was intended to increase understanding of why a particular feature of a school is valuable (Kelly, op cit) and thus intended to raise awareness of the factors underlying successful inclusion.

Teachers in each of the six selected schools, which had a specialist ASD base, were asked to select four pupils (two diagnosed with ASD and two who were not) in the same year group to participate in the study whereupon participant consent was gained from 24 pupils (half diagnosed with ASD) and parents. In relation to the solution focused approach, pupils were asked:

- To rate how happy they were at school (on a scale of 1 to 10).

- If they had ever been at higher or lower parts of the scale and what was happening at those points in time.
- What would be different if they were at the next point up on the scale and to describe what they would see themselves doing.
- Given three wishes to change anything about their school, what would it be.

The answers to this question were often chosen as the initial constructs for more detailed elaboration in the Hinkle (Hinkle, 1965) ladder exercise. Due to the nature of this literature review the findings from the non-ASD pupils will not be commented upon. The findings indicated that pupils with ASD:

- Thought the general help received in school was good and included support assistance, work being broken down, time to think and additional time to complete work.
- Were complementary about having access to the base in their schools which helped them relax, catch up with work and maintain friendships.
- Had many positive things to say which related to peers being friendly, nice and reliable.

Contrastingly, negative responses included:

- Being bullied for being different (this factor proved crucial when the ASD pupils were asked to rate overall happiness), in the playground but not in the base.
- The transition from primary to secondary school being a time when school was enjoyed less than now.

- Concern centred on the size of the school, the number of teachers and new pupils.

In addition to the above themes the higher-order constructs revealed that pupils with ASD were still fairly concrete with regard to the reasons why they felt the way they did. Surface level constructs, such as the wish for friends, nice teachers and easier work, were all seen to be related to making school more fun in order to be happy.

In discussing the findings, the authors of this study stated that seeking to expose higher order constructs had value in relation to what is considered to be good inclusive practices from the perspective of the pupils with ASD. The authors commented on the value of the methodology for seeking the views of young people with ASDs through use of the laddering technique, which proved very useful in enabling all pupils to elaborate on their answers and consider why they felt the way that they did. This was considered to be one of the most important implications of this research, over and above the actual information gathered from the sample of pupils.

In the final strand the views of the young person of having a diagnosis of ASD/AS are reviewed.

2.9 Strand 4: Young Men's Experiences of Having a Diagnosis of AS

This strand considers recent studies investigating the impact of having a diagnosis of ASD on young people and incorporates sections on sharing the diagnosis, perceptions of Autism and young people's experiences of Autism.

2.9.1 Sharing the Diagnosis with Young People with ASD

Huws & Jones (2008) noted that, while there is a considerable volume of findings concerning parental experiences of, and reactions to, the sharing of a diagnosis, there appears to be little evidence concerning the experiences of the young people. Sharing a diagnosis may enable the person concerned to make sense of the difficulties or differences experienced, thus providing reassurance and increasing self-esteem. Alternatively, the reaction may be very negative and the disclosure perceived psychologically and emotionally threatening (Shtayermman, 2009). The focus of Huws and Jones's (2008) UK study was to explore the views of young people who have AS and their accounts of being told about their condition.

The study was conducted at a college for students with ASD where all participants had AS. Nine students (six male and three female), aged from 16 to 21 consented to be involved in the study. Each student was interviewed individually in a semi-structured format, having previously been given a written outline of the scope of the study. The interview focused upon three open-ended questions:

- What is Autism?

- What does Autism mean to you?
- If you were asked to explain your Autism to someone who had never heard of it, what would you say?

The findings of the study concentrated upon responses concerned with the diagnosis of Autism and the sharing of that diagnosis. Interpretative phenomenological analysis (IPA: Smith, 1996) was adopted to analyse the data. Five sub-themes were revealed including disclosure delay, providing explanations, potential effects of labelling, disruptions and opportunities and acceptance/avoidance.

The delay in disclosure appeared to be associated with a range of reactions, but notably feelings of shock or disappointment and a reluctance to believe or accept the diagnosis. With regard to labelling, positive effects included a greater appreciation among other people of the difficulties and a reduction of negative treatment. In respect of the theme of disruptions or opportunities some of the students found the sharing of the diagnosis overwhelming.

References were made to some initial difficulty in accepting the diagnosis but a gradual learning to accept it. On the other hand, being identified with Autism was seen as having the potential to create new opportunities such as access to specialist support services. However, there were participants who maintained their reluctance to acknowledge the Autism and who talked of not wanting such a diagnosis and actively avoiding any information concerned with Autism.

Huws and Jones highlight the likely negative reactions of the young people if the diagnosis of Autism is shared with them a long time following diagnosis. The students in this sample appeared to have had no awareness about their diagnosis. In most cases the Autism had remained an invisible presence in their lives for a significant time. The authors highlight that there is a lack of research concerning the experiences of parents or professionals in respect of sharing the diagnosis of Autism with the children or young people.

The authors acknowledge the limitations of their study, such as the small sample size and the absence of parental contributions to the themes explored. However, they suggest on-going research into the timing and process of sharing the diagnosis of Autism with the children and young people concerned to increase their potential involvement in decision making about care and interventions and in the development of Autism-specific services.

2.9.2 Perceptions of Autism

Based on data collected from the aforementioned article in 2008, Huws & Jones (2013) went on to research young people with Autism, perceptions of Autism and on the social comparisons that they made to other individuals with or without Autism. From the IPA analysis, a number of recurring themes emerged pertaining to participants' perceptions of Autism, which the authors highlight in a superordinate theme entitled 'Making Comparisons'. The authors found that depictions of Autism predominantly centred on how participants felt they had developed socialisation skills and independence over time. Further that although Autism was described by all participants as a type

of disability, it was also perceived as being different and not as severe as the disabilities that some other people had. The authors point out that these accounts seem to reflect how individuals compensate for differences that they might view as stigmatising by avoiding what are known as 'by association' situations (Bos et al., 2013; Goffman, 1963). Such disassociation is evident in the references that the young people made to those who were perceived as being 'worse' than them.

In conclusion, Huws (2013) suggests that:

"Future research explores the heterogeneity of the Autism experience, particularly in relation to narrative accounts of the function of social comparisons on concepts of self." (p.6)

The next study builds on the concept of self through an appreciation of what it is like to experience life for young people with AS.

2.9.3 Life Experiences of Having AS

McLaughlin & Rafferty (2014) researched the views of six young people (five boys and one girl) diagnosed with AS and what the diagnosis meant to them by asking the question: 'What is life like for you?'

This UK study involved meeting the young people and holding conversations to allow them to make an informed choice as to whether they wished to be involved or not. The researcher then interviewed each participant in their homes or schools. The interview investigated perceptions about the label of

AS, emotions, views of current school support offered, social life and academic progress. Thematic Analysis (Braun & Clarke 2006) was adopted to analyse the findings.

In this study all of the young people felt that AS had permanently impacted on how they viewed and acted upon the world. The realisation of the chronic impact of their AS centred around comparison to or reaction from the rest of their peers. Academically, this was seen to be a positive difference, in that it was seen as the source of having more intelligence than their peers. Most of the participants described how they felt AS caused difficulty fitting in with their peer group. Most of the participants communicated a sense of AS being somewhat of an unknown. 'It' had no beginning point, there had never been a disruption to the self and so how could they fully understand 'it' without having experienced a typical alternative to which to compare it. In the theme 'Let me be normal', most adolescents expressed having a desire to be treated like the rest of their peers, perhaps as a way to minimise the perceived impact of AS on their lives. All the adolescents had made a considered and active choice whether to tell their peers about their diagnosis. When talking about 'Fitting in', for three of the six participants there was a stronger discourse of peer difficulties than of friendships. However, the other participants were able to identify themselves with an aspect of their peer group. One participant talked about a sense of loss regarding having limited or 'loose' social relationships. Some of the participants referred to receiving unwanted physical attention from their peers (punching, shoving) as well as name calling.

This research highlights the potential ability of young people who have Autism to understand their diagnosis of 'it', to understand and communicate their needs and provide a sophisticated introspection of their social functioning, when given the time and space to do so.

2.10 Summary of Chapter

The new Children and Family Act, which incorporated the advice on SEN legislation and the new SEN Code of Practice Guidelines (2014), advocates the importance of listening to children and parents. It is clear from the preceding sections that it is vital to be able to elicit the views of those diagnosed with ASD/AS about their experiences of having a diagnosis and the impact of such on their education, particularly social aspects to learning. Qualitative research methods have been shown to be an insightful way of obtaining the young people narratives. If EPs are to access the voices of the young people diagnosed they need to ask, not measure, in order to determine what their views and experiences can reveal about how best to adjust the social and learning environment to make it more inclusive to the needs of those with ASD/AS.

In summary, the research discussed in Strand 1 represented qualitative studies investigating parents' experiences of obtaining a diagnosis and the impact of this on their journey to care for their child. The role of mothers was considered as a focus of this journey, as has been their experiences of engaging services as part of the diagnosis.

In utilising qualitative designs (Willig, 2001) researchers have identified those factors that allude to personal experiences, which are invaluable in understanding what life is like for parents involved in pursuing a diagnosis and subsequent support for a child with Autism.

In Strand 1 the following have been identified:

- The process of obtaining a diagnosis has been traumatic for many parents.
- The time taken to gain the diagnosis has been a crucial factor in accessing services.
- Parents, particularly mothers, have been seen as advocates/activists in pursuing correct services.
- Family lifestyles have changed, with much stress placed on the family in emotional, social and financial terms.
- Limited professional knowledge of Autism has been a barrier to diagnosis.

In Strand 2, parents' experiences of their son's secondary education following the diagnosis were considered. Many of the issues that arose from the interviews with parents highlighted the vulnerability of their children. The following points were considered to be important for effective practice:

- Parents' views should be listened to more and better advice and training offered at different stages of their child's development.
- Professional working should be targeted towards a more collaborative, integrated and holistic approach involving parents.

- More quality information should be provided to parents and schools.
- All transition issues between classes and schools should be addressed through careful planning.
- As ASD is more widely recognised, early support should be more readily available.
- Effective whole-school training should be developed, leading to an awareness of individual needs and flexible programmes to meet individual social and communication needs.
- Mainstream specialised ASD units were seen as a positive way forward.

Strand 3 incorporated the young person's view of educational outcomes following a diagnosis of ASD/AS. Whilst there exists a paucity of studies focusing purely on young men, most studies reviewed have incorporated both parents' and young person's experiences. The chosen studies reviewed (although not specifically focusing on the young men) provided evidence of young men's views of secondary education, as the sample sizes were significantly higher for young males to females in the participants' quota. Key points emerged from each of the studies:

- Hill (2014) pointed out that, whilst a group of people may share a common diagnosis, their needs may not be the same.
- Whilst it is of importance to look through an ASD lens, it is of greater importance to focus on the unique strengths, needs and interests of the individual young person.

- The use of techniques such as photographs and ladders greatly facilitated the young people's ability to discuss their experiences.
- The importance of involving young people in the planning of provision to meet their needs is emphasised.
- Tobias (2009) points out that support should fit the needs of the student rather than seeking to change or 'normalise' them in order that they can somehow 'catch up' and be fitted to the existing and unmodified school arrangements.
- Communication between staff and parents is essential when determining appropriate goals and areas for ongoing attention, along with a monitoring of the students' own reported experiences, concerns, successes and aspirations.
- Alexander et al. (2005) allude to the value of seeking higher order constructs which proved invaluable in obtaining an insight into the views of young people regarding specific things that they think are important in making a good school.
- The existence of the themes identified shows a similarity in higher order constructs and provides a set of principles which, if followed, should make for a good inclusive school, at least from the perspective of the young people questioned.
- Revealing higher-order constructs is valuable in terms of the heightened emotional impact of the views of young people.

In the final Strand 4, young men's experiences of having a diagnosis of ASD/AS were reviewed and key findings included:

- Huws and Jones (2008) highlighted the likely negative reactions of the young people if the diagnosis of Autism is shared with them a long time after it was made.
- There exists a lack of research concerning the experience of parents or of professionals in respect of sharing the diagnosis of Autism with the children or young people.
- Huws (2013) analysis revealed that, when comparing how they perceived themselves now and in the past, participants diagnosed with ASD generally viewed themselves more positively in the present.
- Individuals diagnosed with ASD sustain a more positive identity of themselves than the negative representations sometimes conferred on them by the general public.
- Future research needs to explore the heterogeneity of the Autism experience, particularly in relation to narrative accounts of the function of social comparisons on concepts of self.

I have over 20 years' experience of working with individuals who have been diagnosed with ASD/AS. During this period of professional practice I have developed ways of eliciting the views of the young person, often with parents (mostly mothers) present, and this has proved to be very powerful in completing professional assessments. I acknowledge the importance of developing more understanding of how young people diagnosed with AS viewed their diagnosis and how this impacted on their lives, particularly in their education.

To date, it is my understanding that no study has specifically focused on the experiences of young adolescent men with AS, of having a diagnosis of Autism and how this has impacted on their educational experiences. I was also interested in exploring mother's experiences of gaining a diagnosis and what this journey meant in obtaining appropriate support to meet the young men's social, emotional and learning needs. This led to the formulation of the overarching research question:

'How has a diagnosis of Asperger Syndrome impacted on the educational experiences of the young men?'

In order to address this four sub questions were generated:

1. What are mother's experiences of having to obtain a diagnosis of AS for their sons?
2. What are mother's experiences of their son's education following the diagnosis of AS?
3. What are young men's experiences of their education following the diagnosis of AS?
4. What are young men's experiences of having a diagnosis of AS?

In the next chapter the methodological framework of this research is considered.

3. METHODOLOGY

3.1 Introduction

The intention in this chapter is to provide transparency about the research process. The importance of doing this has long been recognised by qualitative researchers (Cresswell, 1998; Miles & Huberman, 1994; Silverman, 2006). In part, this is in recognition of the stance that research can never be value-free (Denzin & Lincoln, 2000) and also that epistemological and ontological perspectives have a direct bearing on the research process and outcomes (Crotty, 1998; Denzin & Lincoln, 2003).

This chapter provides an overview of the methodological approach to the study. It opens with an exploration of my ontological and epistemological view of the world and how this influenced the research methodological design and analysis chosen to achieve the aims and questions of the research study. The involvement of the mothers as research partners in assisting in the design of the interview schedule and questions for their sons is then described. The thematic analysis of the data is described followed by a commentary on the role of the researcher and reflexivity. Finally, ethical issues are considered regarding this illuminative research. A summary concludes the chapter.

3.2 Epistemological Position

Ontology is the nature of reality. Key questions related to this are what is reality and how does one understand the world as based on how we talk about it. To me, it would seem feasible to suggest that ontology is related to

questions of 'being' and the 'form' of reality. Ontologies are perceived from a range of viewpoints from the understanding that there is one reality to there being multiple constructive realities that are affected by social and political factors (Guba & Lincoln, 1994). Willig (2001) argues that the two main ontological positions can be described as "realist" and "relativist". Realist Ontology maintains that the world is made up of structures and objects that affect relationships with one and another. Materialism, for instance, subscribes to realist ontology by taking a philosophical position that matter is the only reality thereby advocating a desire for wealth and material possessions with little interest in ethical or spiritual matters.

Relativist ontology, by contrast, rejects such a view of the world and maintains instead that the world is not an orderly, law-bound place. Relativist ontology questions the 'out there-ness' of the world and emphasises the diversity of interpretations that can be implied to it. Idealism is an example of Relativist ontology as it maintains that the ultimate nature of reality is based on the mind or ideas. Epistemological idealists such as Kant (cited in Klein 1981) claim that only things, which can be directly known for certain, are ideas. Willig (2001), states that ontology is concerned with the nature of the world. The question driving ontology is "What is there to know?" while Epistemology asks, "How can we know?" (p.13).

Epistemology is a branch of philosophy concerned with the theory of knowledge. It attempts to provide answers to the question, "How and what can we know?" This involves thinking about the nature of knowledge itself, about

its scope and the validity and reliability of claims to knowledge. Research methods provide ways of approaching and, hopefully, answering research questions. Research methods can be described as 'the way to the goal' (Kvale, (1995) in Willig, 2001). There is therefore a need to identify the goals of the research in order to justify choices in methodology. This means that research needs to be clear about its objectives and needs to have a sense of what kind of things it is possible to find out about. Just as Burr (1995) described, epistemology is the study of the nature of knowledge and the methods of obtaining it.

In this research I was interested in relating back to the constructions or meaning making of the young men and their mother's views and experiences of having a diagnosis of AS and its subsequent impact on their secondary educational experiences. The rationale for this being that by gaining the young men's and their mother's views and experiences, it would enable me to develop an understanding of their voices in order to consider the implications for those working with young men diagnosed with AS.

Constructionism is a relativist epistemological position based upon the argument that constructions of knowledge, phenomena and reality are created through perception and social experience (Tesch, 1990). The relationship between knowledge and objects is reversed as it holds that knowledge defines how objects are represented (Lincoln & Gaba, 1985; Schwandt, 1994). Social Constructionists such as Burr (1995), Gergen (1989) and Willig, (2001) assert that human experience is mediated historically, culturally and

linguistically. It can never be a direct reflection of environmental conditions, but must be understood as a socio-culturally specific reading of these conditions. Social and psychological phenomena are therefore seen as constructed rather than pre-existing. Language is an important aspect of socially constructed knowledge. The same phenomenon or event can be described in different ways, giving rise to different ways of perceiving and understanding it, yet neither way of describing is necessarily wrong (Burr, 1995; Gergen, 1989; Willig, 2001).

For this research my epistemological approach was based was on social constructionism which argues that the way of viewing the world is fundamentally that social phenomena do not simply exist, but are the negotiated products of on-going construction, interpretation, and sense making in which social actors engage with others to produce social reality (Berger & Luckmann, 1966; Burr, 1995; Gergen 1999; Gubrium & Holstein, 1997, 2000). From the epistemological position taken, the methodological design and the analysis will now be outlined.

3.3 Research Design

From a social constructionist epistemological position, I considered that a phenomenological approach very much suited the aims of the current research and questions formulated based on the rationale as discussed below.

Phenomenology is a branch of philosophy concerned with the ways in which human beings gain knowledge of the world around them. Phenomenology

identifies current approaches to human understanding and it argues that certain forms of knowing may be more constructive than others.

Phenomenology provides guidance as to how such superior forms of knowing may be achieved (Willig, 2001). Even though phenomenology was conceived as a philosophical system of thought, its methodological recommendations have proved to be of interest to researchers in the social sciences in general, and in psychology in particular. This is because phenomenology focuses on the content of consciousness and the individual's experience of the world (Willig, 2001).

As discussed in earlier chapters, I would assert that the phenomenon of AS does exist. However, rather than studying the phenomenon itself, I undertook researching the participants' experiences and perception of their condition and its impact on their education in order to enhance an understanding of the phenomenon for those professionals and organisations working with young men and their families who have a diagnosis of AS. In my opinion, use of phenomenological methodology was best suited to address the research questions. In this regard, a flexible research design based on qualitative methods was selected to answer the research questions, based on the epistemological view of the world held by myself of social constructionism. The aim was to enable me to gain more understanding of the young men and their mother's experiences. I selected to use semi-structured instead of other methods such as construct elicitation (Repertory Grids) or focus groups because they it meant mothers could be included as co-researchers and participants in the research. Interviews also fitted with the method of data

analysis in which themes could be used to begin to develop a theoretical framework of the participants' experiences. I recognise that construct elicitation based on Kelly's (1955) Personal Construct Psychology which uses the Repertory Grid Technique to gain perceptions of participants could have been utilised but based on my perspective of facilitating the involvement of parents in constructing the semi structured interview questions and subsequently becoming participants in the interviews meant that a much richer picture could be developed as a number of different perspectives were subsequently pulled together.

The research focused on the experiences of a homogenous sample of young men with AS selected from the same gender, age range and stage of development (adolescent), all of whom were willing to talk about their experiences of obtaining a diagnosis and the impact of this experience on their emotional wellbeing and educational outcomes. In order to achieve this, the young men's mothers were co-opted as research partners to help develop the schedule and questions for the semi structured interviews. Parents were also keen to talk about their experiences of obtaining the diagnosis and the impact of this on their son's education. This proved invaluable in preparing the young men for the interviews as mothers (and some fathers) were able to debrief the young men as to the questions to ensure that they were fully cognisant during the semi structured interviews.

As I am employed as a Senior Specialist EP in ASD/AS, this research was advantageous in gaining further insights into the voices of young men with AS

and their mothers in order to make recommendations to improve professional EP practice. Robson (2002) has described professionals researching areas of relevance to their job as having a practitioner researcher role. This seemed an appropriate way to acknowledge my part in this research.

3.4 Research Procedures

3.4.1 Selecting the Participants

In consultation with key personnel from the local and specialist diagnostic centres short presentations about the proposed research was provided by myself and as a result of this permission was gained to contact participants for the research and a list of parents to contact was provided by both centres. Prior to contacting the participants I drafted letters to be sent to mothers outlining the nature of the research attaching consent forms for those interested to be included. (Appendices 2, 3 & 4).

3.4.2 Contacting Participants

The letters outlining the scope of the research and consent forms were sent to 40 parents, half of whom had received a local diagnosis and the other who had received a diagnosis from a specialist diagnostic centre. Ten mothers responded that they and sons would like to participate in the research (four from local centre and six from specialist diagnostic centre). I then sent a screening questionnaire to elicit mother's views of topic areas to include in the interview questionnaire (Appendix 5). The mothers dutifully completed these and, on reflecting on the questionnaire responses (Appendix 6), I was struck by how much the mothers wanted to share their own experiences of the

journey to have their son diagnosed with AS in order to secure appropriate educational support.

Upon reflection, and after discussions with my supervisor, I decided to include mothers in the interviews so that their views could be incorporated into the research findings. It also became clear to me the importance of involving the mothers in structuring the questionnaires for the semi-structured interviews and preparing sons for this experience. Mothers were then engaged in assisting in the formulation of the interview questions and of the interview schedule. This was achieved through follow up telephone conversations and email correspondence. All mothers were very enthusiastic to be fully involved as co-researchers and participants.

Throughout this process I advised the mothers and sons that they could withdraw from being interviewed at any time and, when being interviewed, they did not need to answer any question they that they did not feel was appropriate. I also reassured them about confidentiality, in that any information would not be shared without their consent. Subsequently one young man decided to withdraw and one young man did not turn up at his mothers house to be interviewed which meant a total of eight young men were interviewed, eight mothers acted as co-researchers and three fathers were happy to participate by being present at the interviews and responding to some of the questions. It is important to note that the main debriefing and preparation for the interviews and contributions made were with the mothers and their sons. Fathers became involved through being curious about the

research and wanting to be present to find more about it. The mothers in this research were much more knowledgeable of the journey to get their sons diagnosed and on ensuring that their son's needs were met. Fathers tended to take a backseat role and presented as contented in their role due to having to focus on other duties such as going to work. It was also noticeable that half of the mothers interviewed had been separated or divorced from the fathers.

The mothers and young men were also asked for their consent (Appendix 7) for the interviews to be audio/video taped and transcribed, with their names altered, so that the information could be used in confidence for the purpose of the research. They were also informed about the nature of the research and how the information would be used to help professionals, schools and other agencies in supporting young men with AS.

3.5 Data Collection

The aim of this research was to gain in depth qualitative constructions of the participants involved in the research project. In this regard, the research is not intended to be representative of all young men with AS or indeed their mothers meanings attributed to their experiences.

3.5.1 Semi-Structured Interviews

Semi-structured interviews are frequently used in flexible qualitative research designs (Robson, 2003). As the main preface of this research focused on the participants' experiences, I felt semi-structured interviews to be an appropriate way of gathering information. The semi-structured interview method of data

collection was chosen in preference to a structured interview, to allow me, in consultation with mothers co-opted as co-researchers, some flexibility in modifying the order of questions and their wording, depending on the response of the young men with AS. This proved to be somewhat of a natural process for me as being an advocate of involving parents as equal partners in the diagnostic process as a practitioner, I would always consult with them regarding their views and ascertain their views about their child before engaging the child in any form of assessment work.

The development of the questions for the semi structured interviews originated from the initial questions sent to parents (Appendix 5) whereupon some key areas to explore were generated which enabled me to draft in consultation open ended questions that would facilitate the gathering of information in the semi structured interviews. Prior to conducting the interviews I sought further advice from my research group and checked that the questions were relevant through trialling with the process with a parent and son whom I was familiar with.

3.5.2 Conducting the Semi-Structured Interviews

The interviews with the parents and young men took place at the homes of the participants at a time of their choosing. The interviews were held in many locations within the UK, which meant that I travelled to many distant places in order to appreciate the context in which the young men resided. This was important as I wanted to experience the local context and appreciate what resources were available to meet the young men's needs. It also fitted into my

view that the environment has a crucial role to play in the development of social experiences and was in line with my social constructionist perspective. This included travelling to North Wales, the Lake District, Devon, Somerset and Nottinghamshire. The interviews were undertaken in an environment with which the young men were familiar and included the home and, in one instance, the dormitory of a University's hall of residence.

Between two to three hours were set aside with each family. This served many functions but particularly in building a rapport with the family, particularly the young men. This was very important in helping to alleviate any anxieties that the young men may have been experiencing and involved pre-interview conversations about the young men's interests, hobbies and lifestyle. It also served as an invaluable opportunity to debrief the mothers in their role as co-researchers, in clarifying any confusion that the young men may have about the interview questions.

Before conducting the formal part of the semi-structured interview, I carefully explained the purpose of the research in order to obtain verbal consent for the interview to continue. All consented to being audiotaped and all but one young man consented to being videotaped. The interviews lasted between 45 and 75 minutes.

All interviews were conducted jointly with mothers (and on three occasions with fathers present) and young men. Mothers were interviewed first, in order to reduce any anxieties, followed by the young men. The carefully planned

interview questions were asked and any clarification required provided by mothers. All the young men were keen to ask their mothers more questions about their development and were noticeably relaxed through their body language (posture and facial expressions) when their turn came to respond to the questions.

During the interviews an interactive approach was used with a conversational style where the language used was adapted for each participant to facilitate understanding. Particular attention was paid to guidance regarding how to ensure effective communication styles and questioning techniques with individuals with AS, such as how to avoid repeating questions, yes/no responses and successive prompts with an aim for uninterrupted narrative (Lewis, 2001a; 2002b; 2004c). The questions were asked in a semi-formal manner over a period of time. New areas were probed alongside any issues current in the young men's life. Throughout this process I was guided by the mothers as to particular cues that the young men were displaying, indicative of whether they required a break or time to process the questions in order to respond and particularly to make the experience of being interviewed as stress-free as possible.

All interviews involved a debrief in order to ensure that the participants were clear as to the nature of the research and their contribution to it. The participants were advised that they could withdraw from the interview at any time and that they did not have to answer any questions that they felt uncomfortable with. Although initially quite anxious, all of the young men were

motivated to contribute their views. It was noticeable how they were willing to seek clarification from their mothers if they did not understand which often led to mothers rephrasing the questions and giving a concrete visual example for the young men to respond. Occasionally, the young men were literal in their responses which needed further clarification in the framing of the questions.

At the end of each interview parents and sons were given the opportunity to ask questions and asked whether they would like a copy of the videoed interview and/or summary of findings when available. All families requested the video tape recording as a memento of the interview.

3.5.3 Justification for Using Semi-Structured Interviews with the Young Adolescent Male Participants with AS in the Research Project

During recent years there has been a growing interest in increasing the active participation of children in decisions made about them and their school life (Gersch, 1996). The Code of Practice 1994, the Children Act 1989 and the United Nations Convention (1989) all highlight the importance of listening to the child. In this regard, the law has recently been changed to place a duty on all maintained schools in England and Wales to consider the views of children and young people (Children's Rights Alliance for England, 2013). Hood, Mayall and Oliver (1999) commented that children are a socially disadvantaged and disempowered group, not only because of their age but also because of their position in society as the 'researched' and never the 'researchers'. Milton (2012) has commented that people with AS are at a

disadvantage in research as their experiences and views are rarely considered due to a biased opinion by research academics that they have a limited capacity to understand the research because of the difficulties they may experience in their social understanding and communication skills. I would argue in favour of Milton's view that, by careful preparation and clarity to the research, the views of individuals with AS has been successful (see Chapter 2 for more detail).

In this regard, the research aimed to emulate the theoretical assumptions of more contemporary approaches which respect young men's views and capabilities (Alderson & Morrow, 2004) and are reflected in the growth of Children's Rights legislation and guidance, such as the Convention for the Rights of the Child (UNCRC in 1989), the Children Act (1989) and Every Child Matters (2003). Here the importance of seeking and listening to the views of young men with AS on matters which affect them are highlighted.

I recognised some of the limitations of using semi-structured interviews as a method of data collection. For instance, in semi-structured interviews pre-determined questions are used but the interviewer is able to change the order in which these questions are presented. The focus of the interview can be negotiated between the researcher and the interviewees. However this process of negotiation requires an element of subjectivity, which could be criticised as being too subjective. Another drawback of semi-structured interviews is the extent to which the research findings can be generalised from a small sample size. Research involving semi-structured interviews as a data

gathering tool is exploratory in nature and thus a scientific hypothesis testing approach is not used.

The schedule used for the interviews can be observed in Appendices 9 & 10.

3.5.4 Mothers as Co-Researchers

As previously indicated in Chapter 1, AS is displayed through difficulties in social interaction, communication and imagination. Bearing in mind these characteristics, I engaged mothers as co-researchers in recognition that the research would be better placed to produce rich data if they were able to assist me in asking the questions to the young men. Mothers played a crucial role in gaining the consent of the young men. They were also a great source of support regarding how to set up the interview to maximise the ability of the young men to feel comfortable and ensure that their experiences were being acknowledged by me. In my experience involving advocates, who appreciate and understand the needs of people with AS, has proved crucial in ensuring that their educational needs have been met and the right resources/support provided to meet their needs.

3.5.5 Participants

In this research a relatively homogeneous sample was selected, so that common themes could be identified from the data analysis process and conclusions could be drawn about the young men and their parents' experiences. All of the young men met the following criteria for inclusion in the study, so that the views of a relatively homogenous sample were obtained:

- The young men were aged between 13 to 19 years.
- They had been diagnosed with AS during their primary school education.
- The diagnosis was either provided by the LA Child Development Team or the Specialist Diagnostic Centre.
- They had attended local mainstream schools.
- They had appropriate language skills to enable them to be interviewed.

All mothers were white adults aged between 35 and 45 years old and were born in the United Kingdom.

Table 3.1: Participants in the Research

Young Men	School Type/Support	Local/ Specialist Diagnosis	Ethnicity (parent description)	Accompanied By	Diagnosis
1 Ryan	Secondary/Mainstream ARP*	Local	White: British	Maria and John	Local Child Development Team
2 Joe	Secondary/Mainstream ARP	Local	White: British	Sue and Tim	Local Child Development Team
3 Ben	Secondary/Mainstream ARP	Local	Mixed: White/ Afro Caribbean	Lesley	Local Child Development Team
4 Alex	Secondary/Mainstream with support	Local	White: British	Janette	Local Child Development Team
5 Callum	Secondary/Mainstream ARP	Specialist	White: British	Delia	Specialist Assessment Centre
6 Tim	Secondary/Mainstream with support	Specialist	White: British	Rebecca	Specialist Assessment Centre
7 Phillip	Secondary/Mainstream ARP	Specialist	White: British	Debbie and Pete	Specialist Assessment Centre
8 Jethro	Secondary/Mainstream with support	Specialist	White: British	Jill	Specialist Assessment Centre

*Additional Resource Provision (Asperger Syndrome)

3.5.6 Researcher's Role

My role as an interviewer was considered to be crucial in terms of encouraging/supporting the interviewees to respond in ways that were least influenced by me as possible. Gilgun (2005) points out that the role of the interviewer is challenging, in that they should be knowledgeable about the historical events that are the focus and at the same time they must be relatively unobtrusive so that interviewees can tell the stories in their own ways. Working with a population of young men with a diagnosis of AS posed additional challenges such as being clear on what was meant by what was said, by rephrasing in simplistic terms to minimise error and by checking with mothers and the young men that the interpretations of what they said was correct.

Prior to the study I have been working in the field of Autism for approximately 20 years and had worked closely with many individuals who have AS and their families. I also had regular contact with individuals with the condition whose age ranges span from preschool to the elderly. Subsequently, I was in a position to use experience and knowledge as a specific part of the research process, both in the formulation of interview techniques and in the data analysis. However, my professional experience also raised the critical issue of being aware that this experience and knowledge could lead me to seek justification for pre-conceived conscious or unconscious ideas meaning that there was a need to be mindful of over-interpreting what was said and constantly checking that what was said was a correct reflection of the understandings of the questions posed to the young men.

3.6 Transcription of the Semi-Structured Interviews

Each audio/video interview was uploaded onto a personal computer to provide a back-up copy then the interview was copied onto a video and memory stick. After this procedure was completed, the interview was erased from the digital and video recorder. All data collected was password protected on the computer. Due to time constraints, I commissioned the services of a professional transcriber who transcribed the entire eight semi-structured interviews in the months following each data collection. Hesitations, repetition and non-verbal communications such as sighs were also recorded but not analysed for the purposes of this research (see Appendices 11 & 12 for examples of mother and son transcriptions).

During that period all printed data collected and transcribed was securely locked away and all non- printed transcribed interviews were saved on a personal password protected computer. Once the interviews were transcribed, each interview was carefully read through in detail to ensure that all the possible data was captured and the punctuation used had not changed the meaning.

3.7 Data Analysis

Thematic analysis (TA) is a qualitative research method that can be applied across a range of theoretical and epistemological approaches. It is a method of identifying, analysing and reporting patterns (themes) within data; it minimally organises and describes the data set in detail. It enables the

researcher to frequently go further than this in order to interpret, at a much deeper level, various aspects of the research topic (Boyatzis, 1998).

TA was selected because, like other inductive analytical methods such as grounded theory, it can identify general themes and describe patterns across data and, through a bottom-up data driven approach, data does not fit into a pre-existing theoretical framework. TA can also be similar to discourse analysis in that it enables the researcher to consider what different versions of reality are created, negotiated and deployed in conversation. Like discourse analysis, it can be used to conceptualise language as a constitutive of experience and enables the exploration of how phenomena are constituted as talk in social settings (Willig, 2001) and social context (Wodak, 1996).

A critique of TA is that sometimes it is seen just as a tool but many argue TA is a valid method of analysis in its own right. Braun & Clark (2006) argue that TA can lead to interpretation of various aspects of the research topic of consideration and is flexible as it can be used for both studies examining a particular theory and those that are exploratory. It provides detailed, rich and complex analysis for different types of qualitative data.

The thematic analytical approach taken was based on a step-by-step guide provided by Braun & Clark (2006), which is described below.

3.7.1 Thematic Analysis – Levels of Analysis Incorporated in the Research Study

I analysed all the parents and then the young men's transcriptions of the interviews. The focus was to treat each interview separately at first in order to be open to themes developed from the interview transcripts before referring to themes that had arisen in other interviews. For the purposes of the analysis, the parents and young men's responses were analysed separately.

The process of data coding and analysis using TA involved six stages including:

1. Reading and re-reading the text;
2. Recording initial themes;
3. Combining sub-themes to form themes;
4. Creating a summary table of the themes and sub-themes;
5. Creating a pictorial representation of the themes and
6. Presenting the research findings.

3.7.2 Stage 1 - Reading and Re-Reading the Text

The first stage of analysis involved reading and re-reading the text of each transcribed interview and gradually building up a picture of the similarities and differences in the data collected and extracting this information to generate initial codes. (See Appendices 11 & 12 for sample of transcriptions)

3.7.3 Stage 2 - Recording Initial Codes

I then produced a wide range of initial codes, which were recorded and discussed with work colleagues, External Consultant and University Supervisors. I also discussed the research findings with research colleagues on the doctorate programme and attended an interest group for researchers conducting qualitative research. This proved crucial in enabling me to guard against subjectivity so that a reflexive approach was maintained. (See Appendices 13, 14 & 15 for sample of coded extracts and summary of initial codes for mother and son.)

3.7.4 Stage 3 - Combining Codes to Form Themes

The third stage involved combining the codes into sub-themes and combining these to form themes of concepts that shared the same meaning. The themes were given labels depicting their content. A crucial aspect of the reflection on the themes involved tape recording supervision sessions with my university supervisor and external consultant. This enabled me to reflect on how the sessions facilitated my ability to critically analyse the mass of data collected from the interviews. Four themes and 13 sub-themes were generated from this second level of analysis. Next I reviewed this second level of core categories and themes with my supervisor and external consultant. Following this, I searched for patterns and inter-relations in the data to think about how the themes could be connected in other ways. This resulted in three themes comprising of eight sub-themes being devised in a temporal way so that a narrative could be depicted (see Appendix 16).

3.7.5 Stage 4 - Creating a Summary Table of the Themes and Sub-Themes

The fourth level of analysis involved creating a summary table of the themes and sub-themes for the combined data as shown in Appendix 16.

3.7.6 Stage 5 - Creating a Pictorial Representation of the Themes

Level five of the analysis involved integrating the themes and sub-themes shared by all the interviewees into a pictorial representation of the themes that reflected the experience of the young men and parents as a whole (see Appendix 17 for the original Thematic Map). At this stage I asked a colleague, who is also an EP, to read and provide feedback on the interview transcripts and the thematic analysis for one parent and young man to check that there was agreement with the identification and categorisation of themes as representing a plausible analysis. Finally I presented the research findings to parents at an annual conference convened by Parents of Autistic Children Together. The parents commented on their own experiences and it became abundantly clear that most had gone through similar experiences to participants in the research study.

This strategy helped to provide a 'credibility check', which is one of seven guidelines produced by Elliott, Fisher and Rennie (1999) for evaluating qualitative research. This enabled me to check the understandings of the research participants with others who had gone through similar experiences. It also facilitated gaining verification that colleagues of similar professional background were able to comment on the relevance of the research findings

alongside the creditability checks provided by the external consultant and university supervisors.

3.7.7 Stage 6 - Presenting the Research Findings

Stage six involved presenting the research findings and explaining how the themes relate to the research questions and the research literature and how they illuminated themes previously unmentioned (Creswell, 1998).

In Chapter 4, the findings are presented in terms of what the interviewees experienced and an interpretation of how they experienced it. Throughout this process I 'bracketed' my own views on in order to ensure I was not overly interpreting the findings from my own perspective. This served to guard for reflexivity in the research (See Appendix 20 for sample of reflective diary).

The process of TA enabled a focus on understanding and interpreting themes and on making sense of the interviews as a whole. This process was invaluable in enabling me to come to an understanding of the parents' and young men's experiences of the diagnosis and educational outcomes. The decision to re-create separate summary tables in the analysis for young men and parents was then made in order to allow a comparison of themes arising from parent interviews with those arising from the young men's interviews. This led to me to decide that the focus of my findings should be on three themes which would assist me in a more detailed understanding in order to be able to comment on whether young men and parent perceptions could contribute different knowledge to our understanding of the phenomenon (see

Figure 4.1 p.102). Whilst there was much overlap in themes arising, there were also differences, which will be further reflected on in the next chapter.

3.8 Reflexivity

The aim of this research was to ensure value in the qualitative approach through transparency and authenticity, enabling the research to be trustworthy. The process of reflexivity, as well as explicit transparency of the methodological approach, design and procedures from data collection to data analysis and interpretation, would enable a true understanding of the findings of the project in the wider context, including the views, values and perspectives of the researcher (e.g. Hay, 2005). In this regard, it was recognised that I came to the research with pre-assumptions, beliefs and pre-determined purpose (e.g. King & Kitschener, 1994). Therefore, it was not possible for such an inductive approach to be totally without 'theory' (Hayes, 2000). It was also understood that the relationship between myself, the researcher, and participants was co-dependant and interactive (e.g. Hayes, 2000), with the research being carried out in the domiciles of the participants, which possibly served to minimise the impact of researcher bias.

Given the qualitative nature of the research, it was important that I endeavoured to remain aware that my position and perspective might impact on the outcomes of the research. I reflected on my perspective of being a black middle-aged male whose experiences of being disadvantaged by being denied opportunities to succeed due to a working class background and the colour of my skin, strengthened my resolve to achieve and present as a role

model for others to succeed and by being committed to equal opportunities, human rights and promoting diversity.

It has previously been stated that I have extensive professional experience of families with AS and had previously formed views regarding issues around diagnosis and educational outcomes for young men with AS. It was imperative to remain cognisant of the personal assumptions that there was a need for an improvement in provision and support for young adolescent men in secondary mainstream settings in order to provide a trustworthy account of participants' experiences and views regarding this.

In an attempt to retain thought processes and the feelings evoked by the wide-ranging aspects of this research, a digitally recorded research diary (Appendix 20) was maintained. This was used to record thoughts, feelings and reactions to the many varied demands of the research process. The diary was also used to record thoughts and observations during the transcription and data analysis process, which aided the tracking of thought processes and assisted in maintaining objectivity as much as possible. This was especially important in supervision sessions with my supervisor and the external consultant when considering the experiences of the participants that this was indeed their experiences and not a biased view that I held.

The purpose of videotaping the interviews was twofold. Firstly I wanted to be able to check that the interview process was smooth and did not cause any unnecessary anxiety to the interviewees and if any issues were noted that I

was able to reflect on what changes were required. It also helped me to reflect on my interviewing style and seemed to be a very natural way to revisit the interviews when undertaking the analysis of the data and generating the subsequent themes emerging as part of the audio transcription. The second purpose of videotaping the interviews was to ensure that the families had a visual record of their involvement as a memento to reflect on their journey and for future reference.

I carefully considered a key concern with qualitative research that related to levels of subjectivity within the methodological process and, in particular, whether information/hypotheses stemming from data analysis are generalisable and the problems that language presented (Miles & Huberman, 1994).

In order to focus on these issues and minimise personal/ professional bias, I consulted regularly with my supervisor and the external consultant during supervision sessions, which were audiotaped to enable further reflection of my viewpoint. An audio reflective diary was also used to enable me to record issues relevant to the research and the impact of the research on myself. Support and advice was regularly obtained through emails and telephone conversations. This proved invaluable in enabling me to reflect on the analytical data and indeed led to many revisions on how the data was analysed through Thematic Analysis (TA) based of the Braun & Clarke's (2006) model as opposed to Interpretative Phenomenological Analysis (Smith, 1997). My rationale being that IPA is a research method and analysis best

applied to a homogenous group as such was the intention in my original proposal for the analysis of the data. However, as the research shifted to encompass the views and experiences of the young men's parents this meant that the focus was no longer on individual experiences but now took on a dyad dynamic. This subsequently led me to consider the use of TA that incorporated a phenomenological perspective.

This process of change was directly linked to my reflection on how powerful the messages that the parents, particularly mothers, had conveyed as being part of the research project.

It was important to reflect on the power relations between myself and interviewees, which may have had an impact on the content and quality of the information. For instance, within this research the participants who received a diagnosis from the specialist diagnostic centre may have felt a loyalty towards the organisation because of its specialist role in the assessment and diagnosis of AS, which came about as a result of parents having to pursue this as a consequence of not receiving an appropriate assessment and diagnosis from the local services. Such an experience may have influenced their interview responses and is a factor that needs to be considered from the findings obtained from the research project. Nonetheless the qualitative nature of the research anticipates that this is a factor to consider and I did probe in the interviews parental bias in order to appreciate the nature of such.

3.9 Ethical Considerations

This research adhered to the 'Code of Ethical Principles and Guidelines' for conducting research with human participants and involving children in research (British Psychological Society, 2000), (2009), the British Educational Research Association (1992) and the British Psychological Society Division of Educational and Child Psychology (2002). Ethical approval was obtained from the University of East London Research Ethics Committee, who agreed that the research posed no threat to the psychological welfare or dignity of the parents and young men and that the research would be appropriately supervised. (See Appendix 1).

Participants were given information about the purposes of the research, both in written form and by verbal explanation, intended dissemination of findings, confidentiality and of their right to withdraw at any time. An information sheet and consent form was devised for parents and the young men (See Appendices 2, 3 & 4). They were asked if they would like to receive a video recording and summary of findings at the end of the study.

In accordance with the guidelines, steps were taken to protect participants. It was recognised that the phenomenon being studied might sometimes include discussion of topics considered to be personal and private. It was anticipated that the parents and the young men may be revealing information and perceptions that they had not, up until this point, shared with anyone else. In some cases, painful feelings might have emerged in response to the interview questions. It was felt that the structured nature of the interview would

help to reduce discomfort concerning what might be sensitive issues. Time was given at the interview for debriefing. I planned that, should particular issues arise causing concern for a parent or young man, I would consult, advise and support both parent and young man in my professional capacity as a specialist EP in the field of ASD/AS.

The mothers of the young men were viewed as research partners (Wolfendale, 1999) in several phases of the research process. They were involved in helping to decide on the interview questions and raising issues that they felt were important to them at the pre-interview debriefings. Immediately after the interview, all participants were asked to give feedback. I also debriefed participants at the end of the interviews of the nature of the research. This also served as a check for unforeseen harm, discomfort or misconceptions that the participants may have experienced and for me to arrange assistance as needed. No issues arose or were identified that required further assistance for the participants or myself. Data that was held on a computer was protected by a password that was known only to me. Paper records (i.e. consent forms) and digital recordings were securely locked away. This information will be kept securely for five years following conclusion of the study.

Confidentiality was discussed with participants and their parents throughout. Each participant was informed before the interviews that all personal details and identities would be protected and identifying details would be removed. This was again reiterated at the end of each interview. I kept appropriate

records securely and restricted the scope of disclosure to that which is consistent with professional purposes (i.e. interviews may have been discussed during supervision but no names were disclosed).

3.10 Summary of Chapter

This chapter opened with the research aims and questions, which focuses on the personal stories of the young men and their parents who participated in the study. I have explained the link between of my epistemological view of the world as a social constructionist and choice of research questions, which influenced my decision to complete a phenomenological qualitative research study, using TA. I have described how I have involved the mothers as research partners in the process of collecting the data and how I have addressed the issue of reflexivity in my role as a researcher. An outline of the context of the study and the sampling framework were given. The phases of the research process were described and the data coding and analysis process using TA was explained. An outline of the ethical considerations concluded the chapter.

In the following chapter the data analysis is presented. The factors and processes that supported the young men and their parents, in pursuing educational outcomes following the journey to obtain a diagnosis of AS, is also described.

4. FINDINGS

4.1 Introduction

This chapter presents the findings of the process of obtaining the diagnosis of AS, using quotes to illustrate themes drawn from the data. Through the process of TA, outlined in the previous chapter, three themes and eight sub-themes were generated from the data. The first theme focuses on the families' experiences of obtaining a diagnosis, in which the views of mums (also referred to as mothers) will be privileged. The experiences of Dads (also referred to as fathers) will be included to contrast the journey that mothers have experienced. There will follow a focus upon how the diagnosis has impacted on the family, in respect of coming to terms with it, and the support the family received. The second theme of the family's journey to get the young men's diagnosis recognised by LEAs is outlined. Finally, the findings from the interviews of the young men (lion cubs) will be outlined in the third theme. *Figure 4.1* outlines the Thematic Map of the three themes of the research project:

Figure 4.1: Thematic Map Illustrating the Themes and Sub-Themes

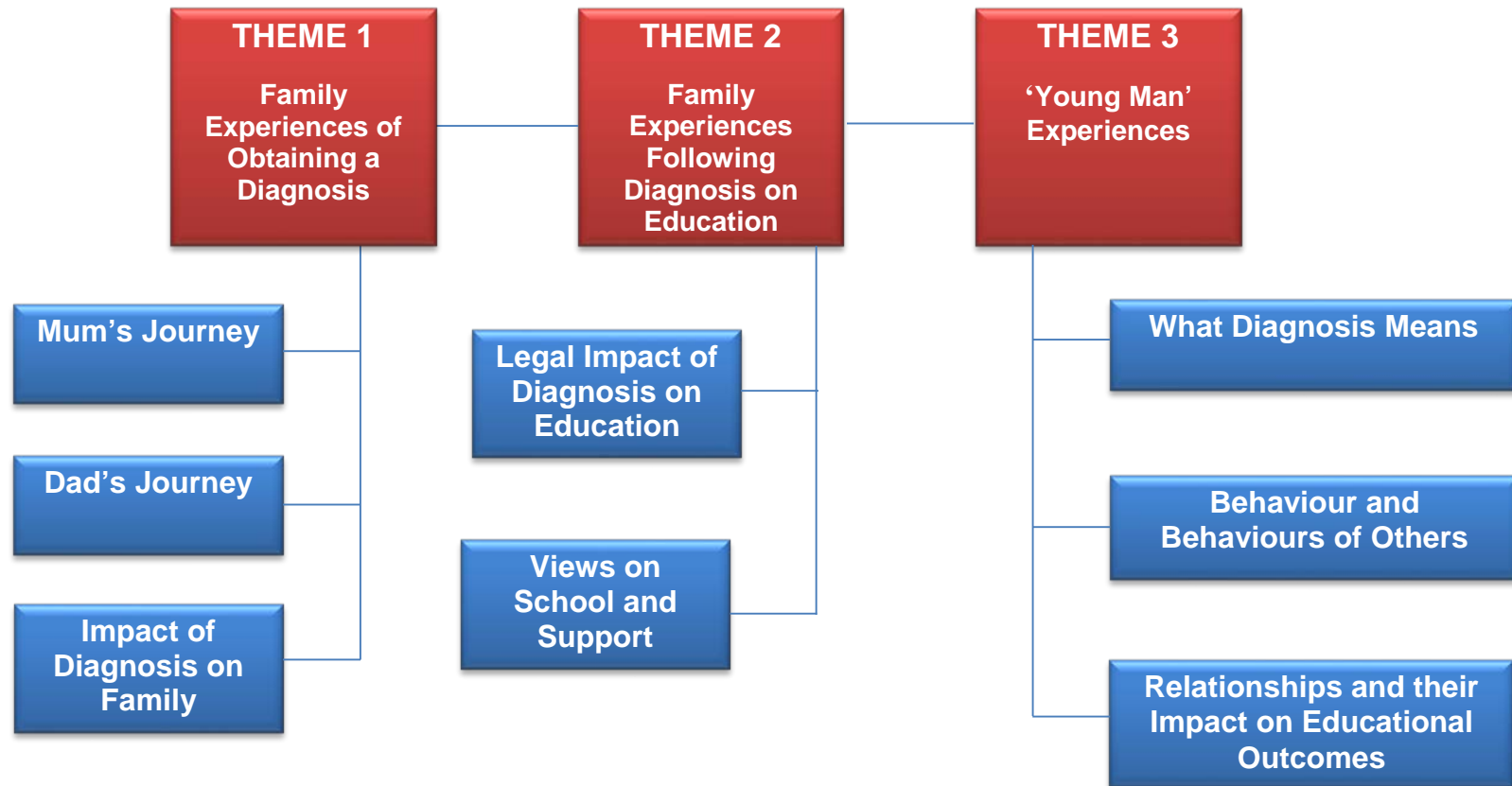
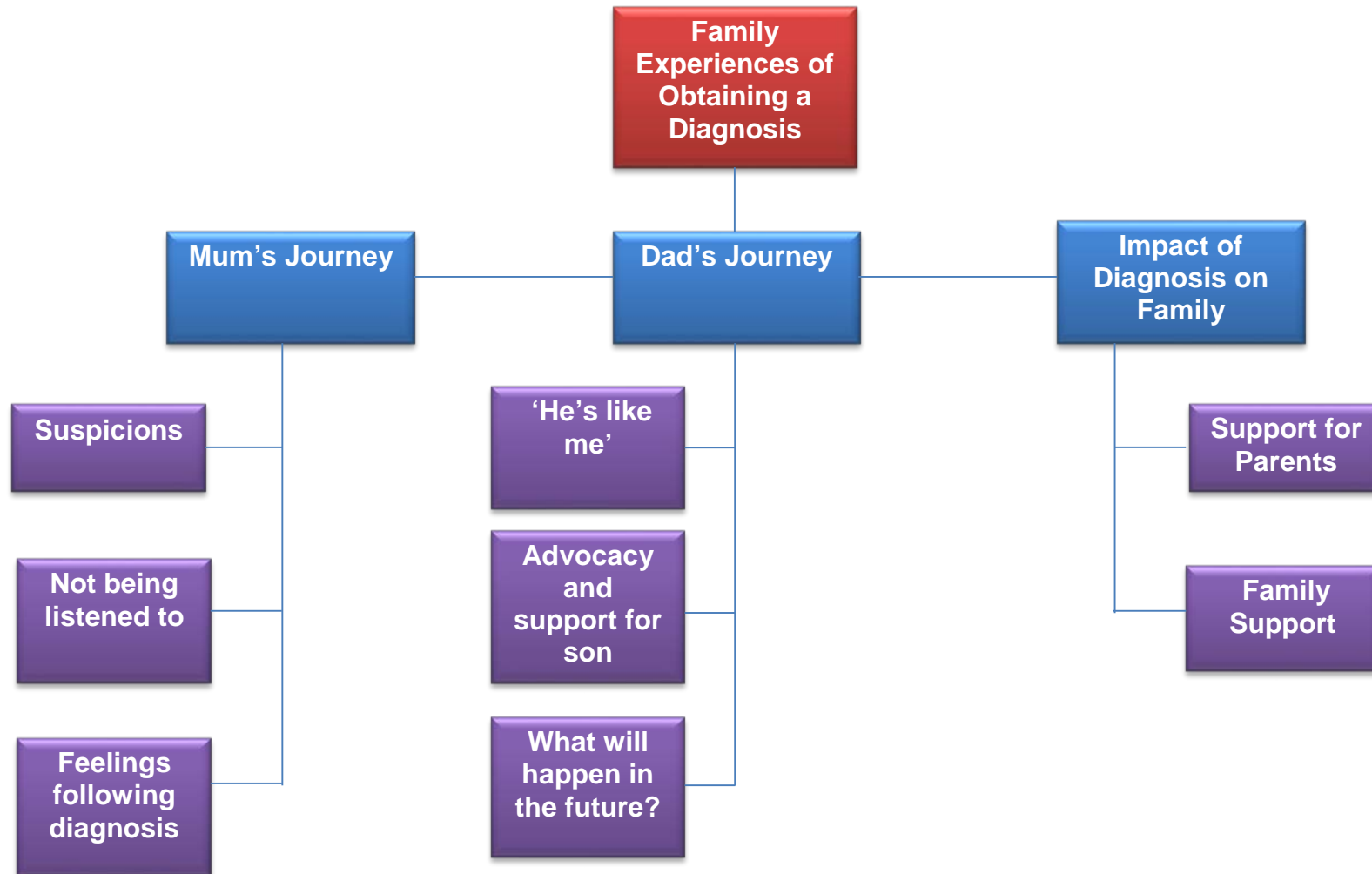


Figure 4.2: Thematic Map 1



4.2 Theme 1: Families Experiences of Obtaining a Diagnosis of Asperger Syndrome

4.2.1 Mum's Journey

Three key areas identified in this subtheme included:

- Suspicions of AS.
- Not being listened to.
- Feelings following diagnosis.

4.2.1.1 Suspicions of AS

Suspicions were reported by mums (also referred to as mothers and lionesses) from a very early age and many examples of difficulties in social interaction, communication and imagination were reported to me to the extent that, by the time sons were of pre-school age, all of the mothers interviewed knew that support was going to be required. The following extracts (Ext) allude to typical concerns expressed by mothers about behaviours of concern from birth:

Rebecca: '.....when he was a baby he just wasn't right um and then when he was two he started just being a nightmare [laughs], an absolute nightmare and it was more than just you know the terrible twos, there was just something not right at all and he wasn't talking or anything.....'.

Ext.14

Lesley: 'Um yeah right from the word go, my fourth child and he was just so different from the others in everything.....'

Ext.24

The extracts above say something about the mother's intuitive nature in recognising that something was not quite right in their son's development and, although not aware of the condition, realised that this was going to require further investigations. This would become more apparent when their sons started pre-school provision and their differences to other children became much clearer. As a consequence of this, mothers became concerned that their son's would need protection and support in the school environment and, with this realisation in mind, sought out more information as to what support was available in nurseries.

4.2.1.2 Not Being Listened To

Mothers continually expressed their concerns at not being listened to by a range of professionals who constantly reminded them that they, as professionals, knew best. This impacted greatly on the feelings of this very determined group of women. In the following extract a mother was told that her son was just being naughty and this was mainly due to attention seeking behaviours – the professionals then allude to having specialist training, implying that they knew best, and were dismissive of mother's view. Many mothers experienced this view and most accepted what the professionals were saying.

Maria: Yes he's been naughty for the sake of being naughty, he's trying to draw attention to himself... and I went into the school later because of another problem that had come up and she says yes but we've had somebody in and we know all about it and he's... it doesn't apply to Jethro he's just being naughty [laughs]

Ext.13

In the following extract mother is clearly being dismissed as an overprotective and unduly concerned parent. This was typical of many of the mothers interviewed in the research. The mothers were told that it was their fault that their sons were the way they were and that, as parents, they needed to consider their parenting skills as a major factor in how their sons were behaving. The concept of the 'refrigerated parent' is very evident here (Bettelheim 1967 – The Empty Fortress):

Delia: "Yeah it was my fault, I was an overprotective mum and there was nothing wrong and so by the time he'd got to school, when he was in... He went to the nursery, he didn't really fit in the teacher took us to one side and said, I don't know what it is but there's something wrong with him. And she said you know it's seen as misbehaviour but he's not misbehaving but he just doesn't seem to understand the rules."

".....and then I went back to the doctors with that and the doctor again said no there wasn't anything wrong with him, he was a fine strap... because he wasn't physically ill, he's a fine strapping little lad and it was me."

4.2.1.3 Feelings Following Diagnosis

Linked to the previous theme 'not being listened to' was the emotional journey of the mothers (lionesses) in which a range of feelings were articulated by them about how it felt not being heard, being judged and being blamed for their son's unusual behaviours. The experiences of this resolute group of mothers, who had striven to protect and find the right support for their sons, are remarkable. This section covers their emotional journey to get a diagnosis (thought by them, at the time, to be the way forward to gain additional resources) and the range of feelings experienced once the diagnosis was obtained from relief to immense guilt and anxiety that a lifelong condition had been determined. In part this section is linked to the adversarial role of this group of mothers but the focus here is much more on the internal values and beliefs that mothers held, which impacted on their behaviours to fight for their son's rights through practical means.

In the following extract a mother talks about being judged by other mothers and her feeling that she was to blame for her son's very unusual and aggressive behaviour.

Debbie : "Well I took him to uh the health visitor who tried to persuade me that he needed social skills, so he needed to socialise and up till that point I hadn't taken him to any mum's and tot's groups because I

just knew what he would do. And so she kind of put a bit of pressure on me

...the first time I did this a mum had to come and get me because he'd poked this little baby right in the eye um and they kind of blamed me for it. I think a lot of the feeling with mums was that it was his upbringing and you know his behaviour was a direct consequence of me.

Ext.43

The implication here is that mother is a faulty parent in her management style of her son. This mother talks about her feelings of inadequacy, of not being able to manage her son's unusual behaviour and of being judged as a parent with poor parenting skills by other mothers. However, implicit within this extract is the mothers feelings of bringing up a child who did not have the prerequisite skills to socialise appropriately with others. Although mother was aware of this, it was a struggle to have this recognised by the relevant professionals and became a real source of anguish for this mother and typifies comments made by other mothers in this research.

In this next extract, mother relays her feelings of being told that her son was raised in a volatile and aggressive environment. She relates this feeling to being very sad, yet angry, at being viewed as a mother who would collude with having a violent husband. This served as another example of mothers feeling that they were to blame for their son's unusual behaviours.

'.....but they justput it down to he looks like a child that's come from an aggressive family um you know is your husband violent towards you [laughs] so I was very upset by that because my husband is not aggressive at all'.

Ext.4

The implication made by professionals was that mother was not able to protect her son and was exposing him to inappropriate and aggressive behaviours that had impacted on his outlook of the world. This mother was made to feel a range of emotions as a consequence of this negative experience of being blamed for her son's behaviours.

Following the diagnosis of AS, an immense sense of relief was experienced by mothers who had constantly been told that it was their fault that their child had behaved inappropriately. The feeling of tension and anger that they were 'banging their heads against a brick wall' had subsided and a general optimism arose that now there was a 'light at the end of a tunnel'. The following extract is typical of many comments made by mothers once diagnosis was made:

Lesley: Oh relief, sheer relief that you know I was rightit was really quite relieving and I really did believe things would happen then.

Ext.14

In the following extract mother talks about her feelings of being relieved that her son's condition was not related to her management of his behaviour. Her perception of her mothering skills as being weak had affected her ability to manage all the children in the family and had taken a toll on her mental health and well-being.

'... I think looking back it does have an effect on your mental health, so you become less able to deal with it and you're constantly just reacting to situations as they come up and you can't think your way around the problem you know. So yes I was very relieved to know what it was'.

Ext.21

In this extract mother talks about her feelings of immense guilt regarding her son's behaviour. She recounts being grateful that she had not caused her son to behave in the way that he had. She further recollects being reassured by the head teacher of her son's school that any unusual behaviour would be dealt with in a positive professional light and, importantly, that the behaviours were linked to her son's condition.

Janette: ... '.....by the time he got to the junior school, um the Headmaster at the junior school had a totally different approach and he would say we've had a problem today, but hey Mrs. B we're going to have these problems, we know that with these children. And you know by the time he left the junior school I had completely lost that guilt complex and I knew it was nothing I'd done.....'

Ext.52

Despite being relieved that she was not to blame for her son's unusual and challenging behaviours, the realisation that he had a life-long condition which would not go away or be treated in traditional medical terms was very hard-hitting and difficult to accept for this mother, and indeed many mothers in the research project.

Rebecca: "I suppose it was um a bit of a realisation as well that this is something that you know that's it now, he's got it, you know it's not going to go away, it's not like a cold, it doesn't get better um that you have to deal with him differently to how I've been dealing with him."

Ext.19

In this next extract, the diagnosis was devastating for this mother, particularly her feelings about his future:

Delia: "Even though I already knew that it was Asperger's more or less I came home and cried, and the way I saw it that was the end of it, he'd never have a normal life because I hadn't heard any stories of anybody with a child with Asperger's who then went on to have a normal life whatever normal is".

Ext.15

Here this mother, despite her anxieties and guilt, greets the diagnosis with more resilience.

Janette: "Obviously you're a little bit anxious um and didn't.....fully understand what was going on to start with, um but at the end of the day they're your child and you cope with whatever comes along."

Ext.41

In summary, this subtheme has outlined the findings from the interviews with mothers of their experiences in obtaining a diagnosis and appropriate support for their sons.

4.2.2 Dad's Journey

In this section the findings of the experiences of dads (also referred to as fathers) are presented including:

- 'He's like me'
- Advocacy and support for son
- What will happen in the future?

4.2.2.1 'He's Like Me'

All the dads who participated in the study made reference to their sons being 'like them' in their personal characteristics and behaviour. This often became a source of much anxiety, particularly when they disagreed over expectations, which on occasions could be so severe that mothers had to intervene and mediate as both were not willing to back down. The strong willed

characteristics of father and son were often a source of disharmony in the family. Subsequently there was a sense of relief when the diagnosis was made and recognition that help was required to deal with the stressors of having a son with AS.

In this extract dad expresses his guilt of transferring his personal trait to his son. He recognises that he lacks patience, has a quick temper and that his son has similar characteristics.

John: "I mean I've not been a very good role model because I have got short patience and a short temper and I can be destructive when I lose my temper."

Mum: "You're both the same in that respect."

John: "And I feel... I feel I've given that to Joseph and I feel very guilty for it and I feel very sad about it."

Ext.89

Here, dad recognises that he needs help in order to be able to appreciate his son's needs. He talks about his own shortcomings as a father and of not being able to cope himself. This has created many emotions ranging from frustration and anger to desperation. There is something here about dad realising that his life has not been productive and his desire to ensure that his son does not follow his pathway.

4.2.2.2 Advocacy and Support for Son

Once diagnosed, fathers become much more involved in supporting mothers in addressing their son's needs. It enabled dads to be more appreciative when explaining their son's often confusing behaviours and, more importantly, what could be considered to minimise the concerns regarding these.

In this extract dad recognised, at an early stage that his son's diet may have been impacting on his behaviour. By supporting his son, through having the appropriate diet, he was able to observe and experience significant changes in his behaviour.

John: "...because we thought he had a poor attention and they said sometimes it can be improved by diet and we did try cutting out lots of stuff from his diet..."

"And J was really, really helpful and actually stuck to it because it's all the things they like and it surprised us at the time and I think it made some small difference. Whether it was the fact J was focused on it and that made a difference I don't know."

Ext.43

Dads often gave examples of how they sought to ensure that son's needs were recognised and appropriate strategies were applied to minimise stress and anxiety in their son's behaviour.

In the following extract this father, although very concerned about the diagnosis, realised the potential strengths in his son's musical ability. He then sought to find the best educational opportunities to nurture his child's exceptional talent.

I found that you know I could encourage him and you know give him little uh... little things to do on his guitar and then he met people through me um in music through people at church and people at school who were musical... musical people who um you know encouraged him and that was it. I mean if you encourage someone um and you give them an opportunity then that's giving them a positive experience and that was what he needed, he needed a positive experience because the reason he was being violent was probably because he was frustrated... I think it was part music therapy really that helped get us through that time."

Ext.34

Here dad, in recognition that his son was becoming very frustrated and that this was being manifested through aggressive and violent behaviour, realised that his son needed to be motivated through activities that he found enjoyable. In this instance his son's interests range from playing with bricks to playing instruments. Dad embarked on a quest to ensure that his son's interests were fully nurtured and developed in accordance to his abilities. In this case, son's musical abilities proved to be exceptional and enabled him to access educational opportunities that he had not previously enjoyed.

4.2.2.3 What Will Happen in the Future?

This one example encapsulates worries about the son's future. It depicts a common experience that all fathers mentioned regarding their son's vulnerability socially, particularly when communicating with strangers.

John: "The only thing that worries... he will walk up to anyone and ask them any question and some of the questions he might ask you think that's a bit too personal and you feel embarrassed but most people, because he's a child, they will answer him in... with no worry whatsoever."

Ext.69

The issue regarding the son's ability to read social cues and act appropriately is of considerable concern to this father, and indeed many others in this research project. Many dads expressed that they were worried that their sons would end up being picked on or ostracised as a result of their social inadequacies. This highlights the need for further training and support for parents in addressing the social and communication needs of their sons.

4.2.3 Impact of Diagnosis on the Family

This sub-theme focuses on the findings from the family experiences of coming to terms with the diagnosis of AS. It encompasses the family's general feelings about the diagnosis and how much support they received to enable them to make sense of how the condition would affect their lives. The support

and the variability of the support that the family received are presented. The key areas commented on are:

- Support for parents – coming to terms with the diagnosis.
- Family support.

4.2.3.1 Support for Parents – Coming to Terms with the Diagnosis

This area explores the family's experiences of obtaining the diagnosis and their feelings about how they were informed and supported by professionals. In this extract the support provided by professionals is seen positively by parents:

Sue: "Well we'd heard of Autism but I'd never heard of Asperger's before. Obviously you start reading up on it and you know get books and read up on it. But of course in touch with the local support group and..."

Pete: "They were brilliant as well weren't they?"

Sue: "Yeah, we... we have learnt most stuff from them you know any problems we could just go in there. Um and then from then on it was meetings with the pediatrician, the speech therapist..."

Ext.13

The parent's feelings of security are highlighted by the positive support received to help them understand their son's needs better. Here, the family expressed their gratitude at how brilliant the local services were in making the diagnosis and providing information as to the nature of the condition. Parents

talk about being aware of Autism but not of AS. The support received instilled confidence to enable this set of parents to conduct further research in the field in order to gain a better understanding of their son and his needs. In contrast, the next mother expresses her frustration at not being helped by those making the diagnosis, even in the form of practical advice or counselling. The impact of the diagnosis left the family feeling bewildered and distraught before they became aware of a local support group. Again, this highlights the important role of parent support groups and how parents had to find out info for themselves.

Delia: "I had to find out myself, I went to PACT and found out through PACT and I started to read about it, I read a lot of books on the subject. But, when he was diagnosed I was just told, yes that's it, it is Asperger's and bye bye, see you in six months."

Delia: "No there was no counselling or anything suggested and that was very hard. But I was fortunate that somebody had told me about the Asperger's Support Group, PACT. So consequently I went along there and then I started to learn more."

Ext.17

Finally, in this extract, the realisation of having a son with AS 'hit this parent hard'. She talks about the condition and the way she had managed her son was wrong. This served to cause her much guilt and anguish that she had also colluded with professionals regarding her perception of her son's needs, in that he needed better parenting and in particular behavioural management.

“I felt guilty because I obviously hadn’t been dealing with him in the right way, you know the way I was telling him off and stuff and grounding him and things, that it wasn’t... that’s what you do with a normal child and it wasn’t the way to deal with my son and if I’d known that years ago I think things would have been very different. Um I think the rest of the family felt the same really.”

Ext.22

The range of feelings described above says a lot about the uniqueness of the experience for each family and also about available resources to help families come to terms with the diagnosis.

4.2.3.2 Family Support

This area explores the support and resources available to the family following the diagnosis of AS.

In many instances the families talked about the need to be resilient and supportive without the need for professional support. In this next extract the mother talks about getting on with what needs to be done to support her son and, implicit within this, is the strength of character that she and her family bring to supporting her son.

Janette: “Obviously you’re a little bit anxious um and we didn’t fully understand what was going on to start with, um but at the end of the day they’re your child and you cope with whatever comes along. So um you know we’ve always been an open family and we’ve always

discussed everything um and hopefully you know that... that has helped us you know not just the immediate family but our other relatives as well you know fanning out."

Ext.41

In the extract above support from within the family can be seen as crucial in enabling all members to come to terms with the diagnosis. Communication seems to be the way forward, alongside a functional and practical approach. Support for this family was minimal in the following extract and very distressing for this mother to experience her son being medicated as a means to control his condition.

"I suppose I could have joined a support group of some sort or whatever but because we're out in the sticks here, I don't drive so there's nothing near hand for us, we did uh... he did go to see a child psychiatrist and they put him on Ritalin from quite an early age, um I think he was seven when he went onto Ritalin and I took him off when he was eight [laughs]."

Rachel: "Uh because he was a zombie basically."

Ext.57

The impact of too much medication being given to a very young autistic child was illustrated in a disturbing manner by this mother's account of the support she received from her GP regarding her son's diagnosis.

“... Now that he was eight year old, um we’ll give him some antidepressants and the antidepressants will probably um he won’t be able to sleep so we’ll have to give him a sleeping tablet as well. We decided that we’d rather have the real Callum than this child who just sat there just to please his teacher basically, sat there and did nothing.”

Ext.57

This mother also talks about the real reason for medication which was to ensure that the teachers were able to best manage her son and, implicit within this, is the issue of her need to protect her son, despite his challenges to school. This extract also highlights the lack of support and mother relying on instinct that the professional was wrong. A generation previous to her would rarely dare to disagree with a ‘doctor’ or expert in their field, even if they felt it was wrong.

Sadly, the time to get their son’s needs addressed is a crucial factor for many of the families interviewed. In this instance it took nearly four years to get support and involved lengthy and expensive legal procedures.

Lesley: “Um well basically nothing, the school wouldn’t accept him, Social Services wouldn’t accept him um and the solicitor carried on our fight basically didn’t he? We went to the High Court in London three times and finally got a High Court Injunction against the LEA, but that was... having had the diagnosis when he was 12 that was four months before his 16th birthday, it took us all that time.

Ext.20

In this excerpt, mother talks about a "battle" and of being a "fighter". She also talks about the real concerns regarding her son's well-being and the involvement of police in helping her.

Rebecca: "Uh yeah [laughs] with a battle, yeah a constant battle."

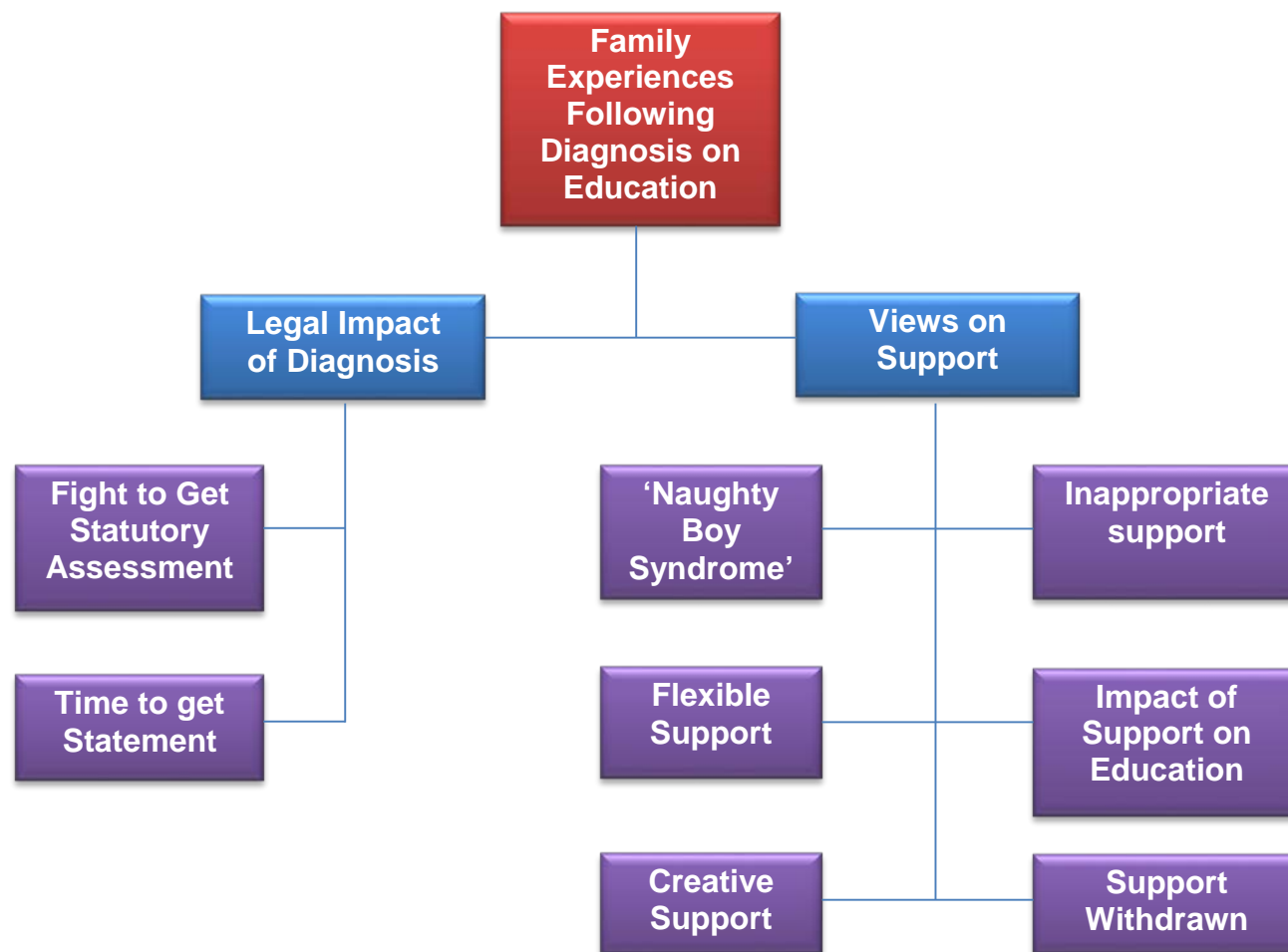
"I think I first went to Social Services when he was about five or four or five when I was really struggling and I said I need help, I can't cope with it um and they said they didn't have any resources to help and there was no funding for Social Workers and all the rest of it and they didn't qualify so there was nothing. I think I tried again when he was about seven um and nothing happened and then I think it was when we started having the real problems with him when he was about 12/13 that eventually they did start taking notice. Um but I was having to go there virtually every day and say to them you've got to do something because I thought he was going to end up dead the way he was going, you know it was just... and the police because he was running away all the time, the police were saying you know the places we're getting him out of he... he shouldn't be."

Ext.44

The extract above is typical of many comments regarding the young men being considerably let down by all agencies throughout their lives.

This sub-theme concludes the findings from Theme 1 on the family's experience of obtaining a diagnosis. The focus of the next theme is on family's experiences of son's education once this diagnosis was made (see *Figure 4.3*).

Figure 4.3 – Thematic Map 2



4.3 Theme 2: Parents' Experiences of Educational Outcomes for Sons

Once the diagnosis was obtained, the journey for parents to get appropriate educational recognition and support remained a crucial area to pursue. This led to two sub-themes evolving from the research including:

(A) Legal impact of having the diagnosis on education.

(B) Views on support.

4.3.1 Legal Impact of Having Diagnosis on Education

The research findings identified a range of views provided by the families regarding their experiences, once having gained the diagnosis of AS and using this to request a Statutory Assessment of SEN to be undertaken by the LEA so that appropriate support could be provided in the schools that their sons attended. Some families had their request turned down and had to take further action, including legal advice, to continue to fight for their son's rights through the tribunal system in order to ensure that their son's needs were acknowledged.

The time taken to obtain a Statement of SEN also proved to be very significant and of much concern to all families involved in this research project. Their concerns sadly did not end with the Statement being issued as further complications often arose regarding the appropriate specialist support required. Support for parents regarding their journey to get their son's needs recognised also proved to be an issue of considerable concern.

The main issues identified in this subtheme are as follows:

- Fight to get a statutory assessment of SEN.
- Time to get the Statement of SEN.

4.3.1.1 Fight to Get a Statutory Assessment of SEN

There were many examples of mothers having to pursue legal support and advice to get their sons needs recognised by the LEA and other agencies.

The following extract typifies the journey experienced by mothers:

Lesley: "We went to the High Court in London three times and finally got a High Court Injunction against the LEA, but that was... having had the diagnosis when he was 12 that was four months before his 16th birthday, it took us all that time to get a statutory assessment."

Ext.20

A sense of frustration is clearly evident in the above extract. This is also coupled with much anger and commitment from this mother to fight for her son's rights, even if this meant eliciting the support of independent agencies. This mother continues

Ken: "And why did you take the LEA to the Tribunal, to the High Court?"

Lesley: "Well because they were trying to blame me for not taking him to school and recognising that he needed support in school, I mean and um we didn't even know where he was, I mean he moved out of

the house when he was 13 and living with all sorts of people, had the police looking for him and if he wasn't seen, I had a whole network of people looking out for him and he wasn't... he wasn't seen..."

Ext.21

This extract typifies concerns expressed by many families of being blamed for their son's difficulties, in particular the young men's reluctance to attend school. On closer inspection it is evident that their sons were expressing their anxieties about school by truanting.

4.3.1.2 Time to Get the Statement of SEN

Having got recognition that the LEA deemed a Statutory Assessment appropriate, there still remained issues related to the time to get a Statement of SEN issued. The following extract highlights such concerns:

"All the time you know I'd just been constantly fighting to get him statemented and..."

Rebecca: "He was statemented um and he was statemented probably I think he was about 14/15 when he was statemented um but it didn't do anything, he stayed in the Pupil Referral Unit so they put that down as his provision."

Rebecca: "Um so I had to battle with them to get the statement changed and then to try and get him the place that I thought was right for him and it took three years altogether."

Ext.14

The extract above illustrates the frustration experienced by mother who talks movingly about the time it took to ensure that his needs were fully addressed. A sense of ‘a battle’ being fought is also evident here. The time that it took to effect appropriate change is very disturbing when one considers the impact such disruption had on her son’s education.

In summary, the findings in the above extracts highlight the extreme difficulty experienced by families in pursuing the right support and legal recognition of their son’s diagnosis through a Statutory Assessment and Statement of SEN.

4.3.2 Parents’ Views on Support Prior to and Following Statement of SEN

In this section the appropriateness, quality and quantification of support are discussed, as is the impact of having support withdrawn alongside school's flexibility to accommodate young men’s needs. Positive strategies developed by creative teachers proved crucial in promoting positive educational outcomes.

4.3.2.1 School Perceptions – ‘Naughty Boy Syndrome’

Many parents reported that their child was originally perceived as being naughty by the school. The following extracts typify comments made by school staff.

Rachel: “I just found that I was fobbed off a lot in the primary school you know it’s just he is a naughty boy, you know naughty boy

syndrome they used to call it didn't they, um and he wasn't. I mean he was obviously having problems learning and he needed other ways to be taught basically, which I think um you found it easier at college now don't you than you did at... he got bullied quite a lot at school as well."

Ext.24

An example of the behaviour considered to be typical of the naughty boy syndrome is illustrated below:

Lesley: "I got summonsed to the Headmaster and when he came home he couldn't understand... what he was annoyed about was the injustice of the fact that they told him that he'd done this twice and he was quite adamant he'd only done it once and I said oh I have to go back and see them and they said yeah but he did it a week ago or something and I went back and asked him and he said 'yeah I did do it a week ago, but that was different stairs and a different day, I hadn't done the same thing twice'. I used to say to him, if you don't understand something ask them and he said 'what's the point of asking them and they tell me the same thing again?' He didn't understand it the first time. You know all those things they were just so classic and they just never... never looked"

Ext.19

The extract above highlights the school's lack of understanding of the young man's condition and, in particular, the ways in which support was provided to meet the young man's needs.

4.3.2.2 Flexible Support

In contrast to the experiences described in the previous section that the young man was being a naughty boy, some schools had pockets of good practice which proved to be crucial in ensuring the young man's motivation to attend school and achieve. An example of excellent support, flexibly accommodated to the needs of the young man, is illustrated below:

Delia: "But she lets him stay in her room at break times and lunchtime, which is a real problem time for Alex. If he had to go outside he'd get a lot more bullying."

"He'd have a lot of problems and when he does get bullied she's very good at, if he can point the child out she makes sure that they're dealt with."

"I think she makes sure she tells the other teachers to be aware of what the problems are, she doesn't... she doesn't presume Alex will understand, she makes sure Alex understands what's going on. But just generally she's very good."

Ext.36

The extract above provides an excellent example of support. It highlights the need for a thorough approach to supporting young men with AS.

In the following extract the flexibility of the school to accommodate son's musical abilities is highlighted as excellent practice by the family.

Dad: "Uh so and then for the next um you know five, year six, year seven, the next three years he had the benefit of that school's ethos, which was like"

Debbie: "a bit more kind of creative rather than a rigid regime where they would always... it was given that he would be able to play in assembly every day"

Dad: "Every single day you know his music was so important in the school that he was able to do his thing every day and um he was going on residencies um once a term almost ...there was a terrific community of music making and um performing arts that he was able to tap into um and it gave him um an opportunity to explore uh what he was good at and what he was fascinated by."

Ext.48

4.3.2.3 Creative Support

The qualities of the people dealing with the young men proved to be a crucial aspect in enabling them to achieve some success educationally. Personality characteristics were identified by parents as being the most important factor in enabling the young men to feel comfortable about their support workers. The following extracts highlight this:

“And it was... the pattern with his education has always been that the success or failure depends on the actual person dealing with him, not necessarily whether he’s got a TA with him, but the personality of the teacher is crucial, um and we just struck lucky a man called Mr. W and he was superb. He somehow managed to find strategies to deal with his behaviour and he was very understanding and managed to talk to the parents about issues that were coming up.

Ext.65

This parent continues:

“So he arrived on the first week in July of what was 1999 and um he was in the production of Joseph three weeks later playing the electric guitar because the teacher, recognised his skill and said right you’re in, you’re Involved, you’re part of this, this is your skill, you bring it in, get involved and he was playing in the show Joseph uh you know doing electric guitar solos and um he was integrated you know within days.”

Ext.66

The findings of the extracts above relate to parents being involved in advising the school of their son's strengths and sources of motivation in order to ensure that the young men's experiences in school were positive. The flexible approaches adopted by teachers are seen as a reflection of their personalities

in understanding the needs of the young men and willingness to adapt the learning environment to foster motivation in them to achieve.

4.3.2.4 Inappropriate Support

Despite managing to secure the Statement of SEN and having quantified the areas requiring support, there remained a fundamental issue of appropriately trained and experienced specialist support. The tendency was for the school to provide support from unqualified but caring mothers employed as support/teaching assistants who had no experience of working with children with AS and who unwittingly were often a source of anxiety for the young men due to inappropriate understanding of their needs.

The following extract highlights parental concerns about support:

Sue: "My only um... my only thing about the schools is um the support teachers themselves who, you know what I mean when you first take your child to school and they tell you it's an SSA and you think oh, I know what they do, you naturally assume this person's got some kind of experience. Well a lot of these people are women who basically go back to work after having their children. Um I saw an advert in the local paper and they go to college once a week for six weeks and then they can go to a school as an SSA and I don't think that's fair on a child with Autism, with a child that's, I don't know, a bit slow learning, even perhaps with a child with something like dyslexia, but Ryan's condition

you can't see it and all they used to do in junior school was shout at Ryan and then they wondered why he got so angry, so aggressive. ”

Ext.52

Here, this mother talks about the environment and the impact of not having the right structures put in place and how this has had an effect on their son's well being:

Mum: “Well they say, the experts and they know all about it, but... they're still expecting him to conform and be able to do everything and they're not putting even like an adequate chill out place, a room even, that can be sort of calm you down stimulus in it that they can go.

Ext.46

Finally, this extract sums up the issues identified in this theme:

Delia: “When he was in year 1 was when we got the diagnosis. And year 2 the school still wasn't doing anything, it was only interventions in class. But it wasn't having any impact, he was... he was still not learning. And not fitting in with the others as well.a school dinner lady who was sitting with him, you know just to keep him quiet basically. And I um complained about that and the class teacher didn't have any real understanding... well she had a nephew with Asperger's and her nephew had had to go away to school because he couldn't

settle in mainstream and I think she did feel that there shouldn't be children with Autism in mainstream....

Ext.62

A sense of not being listened to prevails here as, having once obtained the Statement of SEN and fighting to ensure that the young men's needs were acknowledged in the Statement, there remained an issue that this didn't happen in practice. This proved to be frustrating for parents and the young men and was a common view held by most participants in the research. Linked to this was the concern that the school knew best and appropriate training was provided to meet the young men's needs.

4.3.2.5 Impact of Having Support Withdrawn

The issue of independence by withdrawing support was felt to be a necessary step by professionals and was a real cause of great concern to parents. The impact of this is clearly illustrated in the following:

Pete: "He was getting on really well for about a year with this support um but..."

Sue: "Yeah and then she took some away didn't she and then they realised that..."

Pete: "It was a mistake and it took him a long time to get over it again."

Sue: "Because they seem to think that if the kids are doing alright, oh we'll take away some of the support... and it's not... it's not that, they're doing alright because they're getting the support."

Pete: And another thing they did too much I think is change the support. In all the schools they've done that haven't they. I mean I know they keep saying oh yes he's got to get used to change but why, if something's not broke why fix it you know.

Ext.48

The impact of having support withdrawn highlights an issue regarding the appropriateness of such actions, without careful consideration of the impact of such changes on the family. Many parents reported that they were not consulted about any changes in their child support arrangements. The impact of being told that the changes had occurred was a source of much distress to many families. The following extract highlights this:

Pete: "His temper tantrums go up, you know he's sort of not happy, his sleep gets even worse, he's... we've had him in tears sometimes here when he's not happy at school."

Ext.49

4.3.2.6 Impact of Support on Education

This section focuses on findings regarding educational outcomes for this group of young men, which ranged from encouraging to very concerning. It highlights the issues that many families have experienced regarding the school's ability to meet their sons, social and communication needs rather than concentrating on educational attainments.

In the following extracts parents are encouraged by son's academic abilities, however, they are concerned about the way forward regarding his social and communication abilities.

Delia: "Um well academically he took off like there was no tomorrow, he was working much better, he was happier and right through year 3 he had missed a lot of school because I didn't trust the teacher to be on her own with him without support and they didn't have anybody for afternoons so I didn't send him afternoons, I picked him up at dinner time and didn't used to let him go in afternoons. Um but just generally he picked up on things didn't you? And all the times he's got older it's got easier because he does learn things."

Ext.52

In the next extract mother talks about her son's psychosomatic ailments, brought on by having to attend school, and how this was resolved through creative teaching approaches.

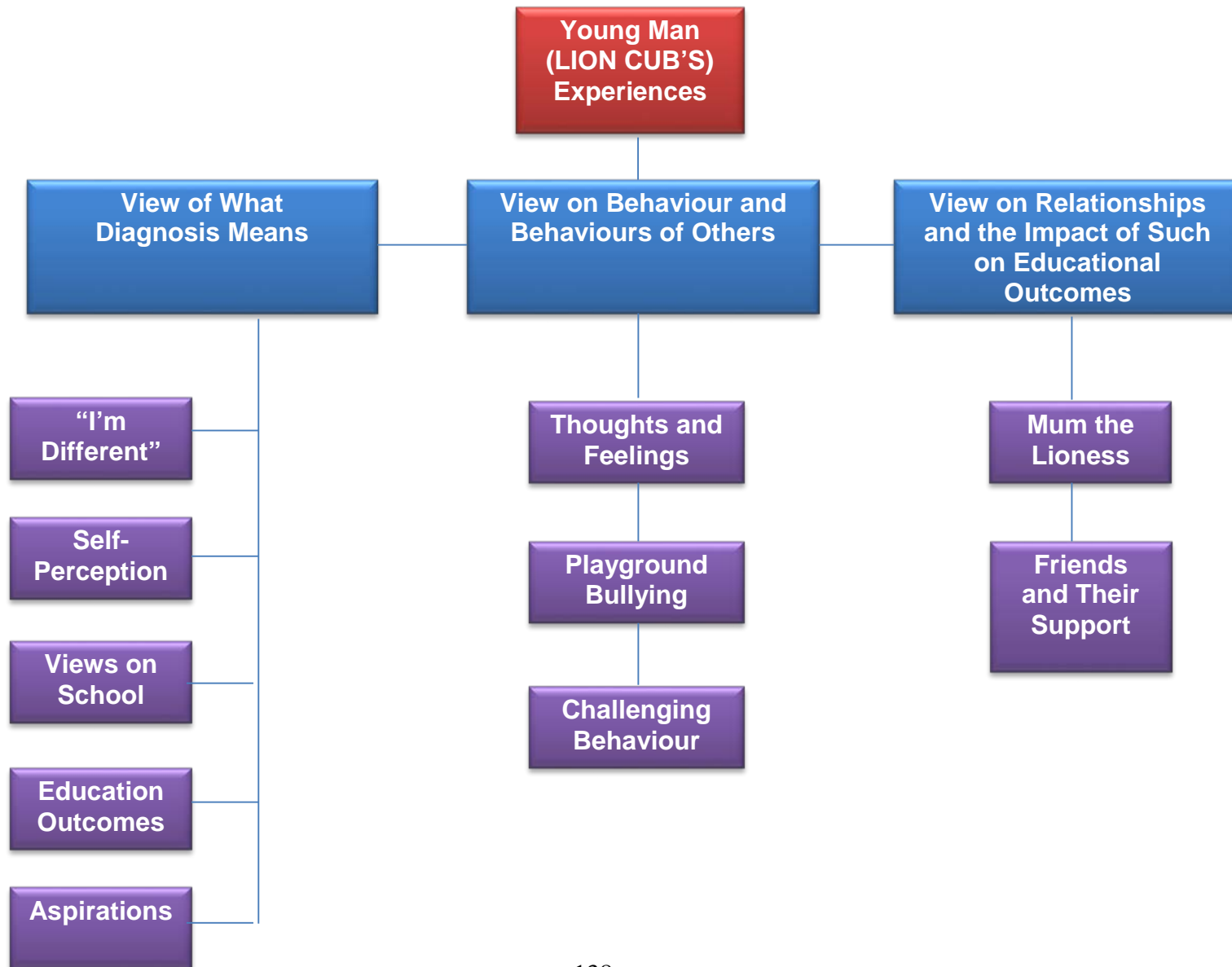
Lesley: [Laughs] "he hated school right from the word go. Was diagnosed with what they call Gastric Migraine because of sickness and diarrhoea every morning and I had to take him to school; he wouldn't go on the school bus even though it was just for school. He certainly didn't go every day of the week even then and I think probably he wouldn't have lasted as long as he did if it hadn't been for the Headmaster in the small school who sort of took him under his wing

and he did lots of didn't you that the others didn't do. You know he always used to say about how responsible he was and he was the only one that could back up the computers and things and put them away and get them out again and he made racks for the dinner ladies, you took all your dad's power tools to school didn't you?"

Ext.73

There is something here about the young man's creative capacity to benefit the school if he was able to pursue his interests. Many of the young men interviewed in this research project had very special talents which did not appear to be recognised by the school.

Figure 4.4 - Thematic Map 3



4.4: Theme 3: Young Men's (Lion Cub's) Experiences

In this theme, three subthemes were identified:

- Young men's views of what diagnosis of AS means to them.
- Young men's view on their behaviour and the behaviour of others in school.
- Young men's view on relationships and the impact of such on educational outcomes.

4.4.1 Young Men's Views of What Diagnosis of AS Means to Them

In this subtheme the findings of the young men's view on their differences to others, how this has impacted on how they see themselves and people's understanding of them are presented. Their experiences of school and educational outcomes seem to have made a considerable impact on their aspirations.

4.4.1.1 'I'm Different'

Here, the young men describe how they became aware of their differences to others as they progressed into adolescence. In this extract the young man talks about being an outsider who became very frustrated about this, which was displayed through difficult behaviours. He talks movingly about how he felt when his teachers accepted him.

Tim: "Um I remember not being the most accepted child now um but yeah I just remember kind of like um just all the um... just never getting

on with anyone type of thing really and always... always being the outsider and um, I can't remember a lot to be honest. I bashed myself about so much I suppose I mean yeah like mum and dad say um there were certain teachers that accepted me for who I was and stuff and um... and that really meant something to me and you know I really... I really liked that and grabbed to that and um... and yeah just um sort of like... I can't think of the words."

Ext.18

The young man goes on to talk about his frustration at not being able to 'get it' when interacting with people. He talks about other issues that made him feel different to his peers, including obsessions. He also talks about how long it took him to develop a self-coping strategy to deal with social interaction:

Tim: "Um yeah I suppose I'd get obsessions and things and I... I sort of yeah just really going nuts and stuff um over certain things I'd get obsessed with and apart from that life was just one big kind of yeah frustration as mum and dad put it and yeah I you know just couldn't... I just couldn't understand other people and things I guess, I wasn't... I just didn't under... you know get why people would do certain things and... and it took years and years for me to figure out that actually you know this is what you do, this is how you act in public and stuff and um... and I just sort of had to learn to copy people's behaviour and things like that and um yeah."

Ext.19

In this next extract mum talks about the need for routine as a means to maximise his transition from home to school and vice versa. This idiosyncratic behaviour was a necessary self-coping strategy to reduce his anxieties.

Mum: "And you used to have this little routine when you walked back from the primary school in Torquay, we'd get to a certain point and he had to go around the lamp post twice and then bang on this um uh like door of a, you know of um a car... what do you call it, garage. Um and I spoke to about it and said look this is going to get me into real trouble because he does it every single day, he bangs on this garage door and he said well if nobody's complaining just let him do it [laughs]."

Ext.29

This quote exemplifies the young man's awareness that he is different to others:

Tim: "..... To give an example like jokes and things like that I'm not... I'm not the best at getting jokes, I think I'll be honest with you I don't... my mind doesn't work like that (?) I do... I do my best but you know I mean it's not... it's not my thing really [laughs]."

Ext.21

The extracts quoted illustrate the feelings experienced by the young men interviewed in the research study of being different to others. They talk about the need for being accepted and there is something there about wanting to be

valued for who they are and not to be judged negatively by others because of their atypical behaviours.

4.4.1.2 Self-Perception – View of Self

The following data is based on the findings of the range of views the young men expressed about the diagnosis of AS from being positive to negative. In this extract, the young man speaks positively about having a diagnosis of AS. To him it is a gift, as he recognises that he has many talents and abilities:

J: "Well two things, I wouldn't call it a problem."

J: "[Pause]... and the second thing is that Asperger's is also a gift like um brains... I can't think of the other word they say but it's to be used for the good of mankind."

J: "Like I'm better at science and other things, they wouldn't think I was going to get a level 5 and I did."

Ext.9

In the following extract the young man does not understand or feels unduly concerned by his diagnosis. He is what he is and does what he does:

Phillip: "I still don't really understand it now, I just get on with it you know, just do what I want to do at the end of the day."

Phillip: "I ain't worried about it really."

Phillip: "I don't really understand it, no. People try to explain it to me but I'm just... it's something I'm not interested in"

Ext.17

In this extract the young man interviewed logically explains his condition:

Alex: "Um it was... it was just... well I don't know if you could say discovered, um I'll use that term for now, discovered for want of a better word if discover isn't the proper word, um by someone whose surname was Asperger. Um I know that I did something in year 5 on it um but..."

"It just means I'm a bit different and everyone's a bit different in a way."

"I know that my brain works differently, that was one thing yeah. It gets a bit complicated around then and I can't really get my thoughts together on that bit, I'm not entirely sure."

"I don't know what anything else feels like because I've been like that all my life."

Ext.11

This young man perceives his condition as being a mild form of autism, which has affected how his brain works in that he thinks in a literal way:

Tim: "Well it's... I kind of remember that it is sort of a well mild form of Autism and the brain works differently basically I guess. Um you just, you don't... well what I found to me it is it's not quite thinking logically, thinking more literally certain... you know it's one of the things I've found. Um..."

Ext.20

In this extract, the young man perceives the condition in negative terms affecting his learning capacity:

*Callum: "Well it's basically just a learning disorder isn't it, you can't...
you find it hard to learn certain things to do with all sorts really."*

Ext.13

The perception of having the diagnosis ranged from being positive, negative and apathy in the research group and highlighted the need to provide more information regarding the condition to those being the recipient of the diagnosis. As this group typically have difficulties expressing their emotions, the comments do not convey the inner feelings but more the thoughts about the condition in a theoretical manner. The quotes could be seen as the young men trying to theorise, conveying their thoughts about the matter rather than feelings.

In the following extracts the young men describe their way of dealing with the stressors of being in a social world and of people's understanding of their behaviours. In this extract this young man who relates his behaviour to the character with AS in a famous book highlights the need for a safe haven, where one can calm down, as a useful strategy:

J: "[Pause]... well I'll go off topic, but when I talk about it being like this I wasn't... well I've got this area, this chill out zone and I go to that.

Sometimes it... it does calm me down, chill me out and all that but sometimes it doesn't, sometimes it just makes me angrier because you're in a subdued area, space. Sometimes I... sometimes I like um when um whatever, you know sorts of emotions you feel and sometimes I feel like um hiding in the boiler room."

"It's a small area, it's like um... have you read the Curious Incident of the Dog at Night Time?"

"Well you know Christopher he like hides in small places like the book."

"It's like if you can understand him you can mostly understand me."

Ext.34

This young man talks about his tendency to see things in black and white relate to certain morals of doing the right thing, even if it means getting into trouble and offending others. This is used as a reason why a chosen profession (law) is being pursued.

Alex: "Alright well Miss M was my um art teacher in year 8 and she had a few problem children, well you know naughty children in there who were... so and I felt sorry for her and the Head of Art was always, well she'd go in and she'd complain to Miss M about how the class was... and she'd you know all sorts of... um I just didn't like the way she seemed to be as it were horrible to Miss M and one day after art, I think

it was a bit silly of me now, but I just went up to her and asked why are you always so mean to Miss M and she shouted me out of the art corridor.”

“I mean most people I suppose wouldn’t have um well thought not to say that but...”

“It needed saying as far as I was concerned. There’s quite a black and white thing with me about right and wrong, that’s why I want to be a solicitor actually, that’s one of the main things. I’ve also been told by people that I’d be a good solicitor. I can see things in black and white, not to say that I’m colour blind, I can see colours, I’m not colour blind!”

Ext.35

4.4.1.3 Views on School

Young men had many contrasting experiences of school and their education. Few had very positive experiences and many experienced negativity, which greatly impacted on their confidence/self-esteem and very importantly on their motivation to achieve. Linked to changes in their physical (puberty), and emotional (adolescence) development, which proved to be a great source of frustration and anguish in their quest to maintain positive relationships with their peers, who by now had often become very alienating and dismissive of them.

Positive Experiences:

In this extract the young man talks about how he has got on well with his teachers due to being taught to show respect to them. This proved to be a very positive experience as he was generally treated well by them:

Alex: "That's very good because at school, at school the teachers tend to like me because I've got good manners... well according to them I've got good manners."

"That's something those they... that's something that teachers seem to like about me a lot because um at the parents evening they tend to say that I've got good manners..."

Ext.39

The need to provide the right training in social skills is highlighted here as the tendency to assume that the young men knew what to do socially was an issue that schools needed to address if they were to provide positive learning experiences for the young men.

The above extracts highlight the need to provide the right training to enable the young men to access the social learning environment. Many of the young men involved in the research project reported experiencing difficulty coping with the social aspects of the school but finding the academic experience less daunting. This proved to be a source of great stress and anxiety in some young men and often led to this being displayed in challenging behaviours

such as not wanting to come to school, displaying inappropriate behaviour in school resulting in exclusion on many occasions

Negative Experiences:

Here, this young man talks about being treated differently but unable to say why. This highlights the issue about not been able to work out what he may have done wrong and in communicating his feelings:

J: "They just didn't know how to deal with me, they just um... well sometimes they were okay but they... they just um tried to deal with me in a in an irrational way."

Ken: "Okay what things were happening at school that that made you experience difficulties?"

J: "I can't remember but throughout the first time I did something wrong they didn't know how to deal with me and then they started treating me slightly different."

Ken: "And how did they treat you slightly differently? What did they do?"

J: "I find trouble answering questions like that."

Mum: "You wasn't allowed out at break time was you J and things like that."

Ext.48

In this extract the young man talks about his dislike of having to be transported to school as this singles him out as being 'different'.

J: "Yeah I want to talk about two things; well first I hate the bus that I go to school on."

"The people on it, the... the um..."

"Yes the... and the pupils and I hate... also hate just going on a bus every single day, I'd rather go out to school by myself."

"It's like um going on a Barking and Dagenham, not like a stagecoach, just like um... like... well if you went on a kiddies bus to work every day you'd know what it was like."

Ext.50

4.4.1.4 View on Educational Outcomes

A range of views emerged from the young men regarding their education. In this extract the young man talks about being excluded and that this could have been avoided if appropriate strategies were put into place. He uses the term 'reverse psychology' to illustrate this point.

J: "Year three, I'm just... and then they kept excluding me and letting me back and we just gave up after a while. They gave us one last chance and we thought..."

"And then they excluded me and I ended up in D. B"

"It was better."

"They could deal with me better. Then um... they started saying not what it really is but, I hope you get me, but like a reverse psychology."

"Well um you know how you punish someone for doing something bad, instead of punishing them, something else they can do instead."

Ext.59

Sadly, this young man's experiences of school have made him angry and the desire to withdraw from school became more apparent as his educational experiences became very unbalanced i.e. that the mixture of good and bad was not equal, with the bias towards his experiences being bad.

He goes on to relate this in an analogy of school experience being like 'weighing scales'.

J: "Well if you think about it school is like the scales, you need a balance of good and bad things to happen because... because it's a... it's a... it's a bit like um weighing scales like... I'm going to say something and then I'm going to explain it, like you have a knock at a wall but you can be forgiven so many times, you take a knock at a person you might not be forgiven."

Ext.60

He goes on to express this was a primary reason for him, wanting to stay at home alone:

*J: "But the place that I wanted to go is I wanted to be home alone."
"But they... and the only way they would let me home is with someone there and that wouldn't be home alone."
Mum: "And if they had a better place for you to go you might not need that thing to fly it home and then if he can't get away from people he's*

angry, then he's going to lash out and they're going to get hurt and that happens frequently in the junior school."

Ext.61

In this extract the young man talks about, despite having the diagnosis, not being supported at secondary school. This greatly affected his motivation, confidence/self-esteem to achieve academically.

Phillip: "Well yeah primary school wasn't too bad; it was quite fun really I suppose. Secondary school was just crap from the start."

"Well like mum was saying, they never supported me, they'd never do me any help when I asked for it or anything and I always got treated like everybody else and it didn't work so I didn't bother going, that was basically it really, short straw."

Ext.52

The young man continues to express that his talents were not nurtured and that he had to seek an appropriate education elsewhere.

Phillip: "I couldn't focus on the subjects; just if I didn't have any interest in it I just... just didn't bother me, if I didn't enjoy what I was doing... straight over my head."

"The woodwork and that, design tech wasn't too bad was it, I enjoyed those doing stuff like that."

Lesley: "No but then you ended up going to night school to do it because they weren't doing what you wanted."

Phillip: "Oh yeah because they were all like a couple of years behind me [laughter]."

"They were just learning how to do their joints and I'm building cabinets [laughs]."

Ext.53

This young man talks about his close friends who understand him:

Callum: "Well I guess my really close friends are my friends because they understand that I'm not the same as well normal people, they know why I get agitated easily and all that so they tend to um you know just ignore me ... They tend to... no I think it works because they know I've got problems and stuff."

Ext.14

Here, this young man talks about being ostracised because of his academic abilities:

Jethro: "Well I think they were jealous of my academic ability at the time and sort of objected to the fact that they had some smart ass in class who could answer all the questions and they couldn't."

"Because he was a smart ass and because he has you know special... difficulties interacting socially."

Ext.17

Many issues regarding the nature of inclusive practices is apparent here as there is evidence of concern from the young men that they were being excluded in school because of their difficulties in socially understanding the nuances of friendships. This had a significant impact on their emotional well-being. A sense of not being treated as an equal is evident here, although some examples of emerging friendships became apparent as understanding of the young man's needs were recognised by peers, who could provide much support to the young men in times of need.

4.4.1.5 Aspirations

A range of aspirations were depicted by these young men based on their motivations and desire to succeed.

In this extract the young man seems clear that it will be hard to get a job as an actor and that he will need to get by doing another job such as an 'ice cream van man'.

J: "... um I'm very good at acting as well and there's some jobs that I could have as a side job when... if I was an actor or something like that, when I'm not doing my job I could be a... my side job could be an ice cream van man."

Ext.64

This young man is committed to justice and his motivation to work in the legal profession is clearly articulated here, as is his desire to put 'criminals behind bars'.

Alex: "Well I want... I want to put the criminals in prison as it were and I want to do something like that."

"The solicitors do the research, the Barristers present it in court and um I like the idea of... I like... I like both the idea of gathering up the stuff for it and then of course also passing it on to a Barrister and if I was to become a Barrister I'd... I'm not entirely sure but I suppose I wouldn't mind going up with the information but I think I'd rather be a solicitor.Well what I really want to aspire to, of course what I want to aspire to at the moment is solicitor but what I want to try to be is a Judge, although even Miss C... although Miss C isn't quite sure about that, she thinks I wouldn't be a good Judge, she thinks I wouldn't be lenient enough."

Ext.65

This young man is keen to be a success financially in his specific interests, which relates a computer programming, but his real desire is to race Formula One cars.

Jethro: "Well uh a job in computer programming in say like a major city company down in sort of London town would be nice that pays handsomely. ... But um as well as that there's sort of there's a dream

that I had sort of many, many years ago sort of locked away recently since I've been at university to sort of maybe drive a Formula 1 car around a circuit."

Ext.72

This young man is pursuing his immense talent in music and has aspirations to achieve at the highest level:

Tim: "Um well um this summer I'm going to um Berkley School of Music in Boston, going to summer school."

"Yeah um I'm quite looking forward to that, um and then hopefully after I finish college I'm going to take a gap year and... and just literally just practice uh my um for a year in my own my room just for a year just to get as good as I can and so I can try and... try and get to Berkley School of Music in Boston in the US for some sort of course."

Ext.76

From the extracts it is evident from the findings that, despite their social and communication difficulties, many of the young men interviewed for the research project held positive aspirations for the future. Although aware of their differences to peers and that they would need to have support in enabling themselves to read social situations better, they were keen to pursue sources of motivation and interest into a productive vocation.

4.4.2 Young Men's View on Behaviour

This subtheme focuses on three sets of findings of the young men's views on how they have communicated their feelings through their behaviour, their views on the behaviours of their peers towards them and the impact of their 'challenging' behaviours to others. A particular area of concern identified by the young men related to transitions.

4.4.2.1 Thoughts to Describe Behaviour Not Feelings

There are many examples in this research of the considerable difficulties the young men experienced when attempting to describe their feelings to others. The following extracts highlight typical examples of young men using their intellect (thought processes) to describe their behaviour, whilst not being able to address how they felt about their behaviour. In this extract the young man talks about the support he received at the child and family consultation service from a very supportive worker:

J: "[Pause]... well she was just... acted um herself, normal um rather than being different for the foundation. Like you know when you can tell when someone's doing something different for a company and she did it for... not for the company, for herself."

"What went wrong, what's going to help ... what we can do to change?"

"It's a bit like problem sharing)"

Ext.5

In this extract, the young man adopts a fantasy analogy to explain his behaviour:

John: "I mean I...he shows emotion in the way that only J can show emotion, he doesn't show it the same way as we would and I don't think he would say... he finds difficulty saying, I'm sorry because... and he... and he feels he wish he could go back and alter or change to do his actions different."

J: "I could when they invent the time machine."

"And the true thing is one day they will invent a time machine one day almost anything impossible.... will be possible."

Ext.6

4.4.2.2 Bullying and Playground Behaviour

Incidences of bullying became very apparent in this research, particularly in the playground. The bullying manifested itself in different ways resulting in a variety of responses from the young men. Examples of such responses are indicated in the following extracts. This theme relates closely to the research question on the impact on education prior to and following diagnosis.

In this extract the young man talks about his experiences in the playground and his responses, which included aggression that could be seen as a coping strategy to deal with bullying:

Ben: "Well they say like just say like really horrible things to me and sometimes they just come up to me for no apparent reason they'll hit me."

Janette: "Or they'll get you to do things won't they that they know is wrong."

Ben: "What like running into stuff and all of that kind of...?"

Janette: "Yeah they'll get you to do things that they know are wrong you know that's going to end up getting you into mischief."

Ext.10

Ben: "...but the worrying thing for you was when um hit me wasn't it in the house like and mum just got worried because of like where I, you know when I hit I do so much damage and he hit me and I hit him but nothing happened to me but his tooth went through his lip when I hit him and that's what got mum a bit worried."

Ext.11

In this extract the young man talks about being different and this was why his peers bullied him:

Callum: "Well basically it was because um... basically I think it was because I was different from pretty much everyone else. Some people don't like people who are different."

Ext.12

Callum: "It wasn't really physical it was more just names and comments and you know leaving me out of stuff and that kind of thing."

"I just felt like I wasn't being accepted and that kind of thing."

Ext.13

This next young man talks about being bullied because of his glasses and physical characteristics and how he has managed to overcome this:

Delia: "He wears the coloured lenses, he went for the colour test and actually, they do make a difference; they help him walk in a straight line."

Alex: "I thought the I... at the start of year 9 I decided on a way of backfiring at it by if anyone ever said 'Elton' or something like that um I'd reply 'hello idiot' just as if it was their name because that annoys them because they have to be an idiot to think I'm Elton John because well I've seen pictures of him somewhere um my hair isn't as ginger ".

Ext.15

In this extract the young man talks about being tormented in school:

Jethro: "Something putting me in corners or something or just sort of tormenting me in the corridors, so you sort of like you'd go in the classroom sort of like away from sort of like a quiet place where you could just sort of keep your head down and relax, just sort of away from the commotion."

Ext.17

In the above extracts, incidences of bullying occurred in a variety of settings including open spaces, such as the playground, where much difficulty was experienced in understanding the social rules. This often meant that the

young men were the subject of cajoling and being made to do things that would potentially get them into trouble. A variety of responses also occurred when the young men reported incidences of bullying, from fighting back to completely withdrawing from the situation. It is important to note that the young men's view of bullying may have been a misperception and highlights the need for support and training in friendships.

The next sub-theme focuses on the young men's views on their behaviour.

4.4.2.3 Challenging Behaviours

Many of the challenging behaviours were displayed primarily as a result of the bullying that the young men experienced which meant that, in essence, many of them did not want to go to school. Other behaviours included anger and aggression towards others as a means to get their needs met. This often included fighting with peers and, in some instances, aggression to adults.

The following extracts, highlight these issues:

J: "I'm just going to stay at home."

Mum: "But you know you're not allow... we can't leave you at home."

You have to be into school, we have to be in at work you don't want to go to school, you think you're not going to school but that isn't really an option that is the problem we have isn't it?"

Ext.19

Ben: "Yeah but whenever I don't have my medication it's just that if I get excluded for fights that's when you get worried. It's more about... about me hitting back isn't it, that's what you get worried about."

Janette: "...but people do sort of, you know children do tend to wind you up a bit don't they because they know that you know, they know if they wind him up enough Ben's going to perform and then they run off and Ben's the one left in the trouble because everybody else has disappeared."

Ext.21

There were many examples of the extracts quoted above, which often meant that the young men were misconstrued in their attempts to communicate their feelings through their behaviour. This impacted on their relationships, which is the subject of findings of the next subtheme.

4.4.3 Young Men's View on Relationships and the Impact of Such on Educational Outcomes

The issue of relationships proved to be a very confusing area for the young men in this research due to difficulties relaying their feelings and being misjudged by others through their behaviour. Behavioural descriptions were often used by the young men to describe how they felt about their relationships with the key groups coded in the research including:

- Mum the Lioness.
- Friends and their support.

The focus of this sub-theme is on the findings of the young men's view of their relationship with their mothers and typifies the lioness /lion cub theme that prevails in this research project.

4.4.3.1 Mum the Lioness

An important finding of this research has been the immense bond between mothers and sons that struck me as the bond that lionesses exhibit in the wild to their cubs. This is because of the role that mothers played in ensuring that the sons were correctly assessed and diagnosed so that appropriate support was provided to enable sons to progress educationally. Implicit within this was the mother's determination to fight to secure that their son's rights were addressed. The attachment of protection by mothers highlights the relationship between mothers and sons. In the research project sons speak movingly of the support they have received from the mothers.

In this extract, recognition of the immense support mother has provided is made by son, albeit in a slightly inappropriate way:

Phillip: "Yeah like getting my head around my bills and that and knowing that when mum's not there to help me, when she's not going to be there to help me I will struggle on my own. So I'm a bit worried about finding someone to replace mum's shoes."

Lesley: "I'll take that... I'll accept that as a compliment for what I have done and some recognition thank you [laughs]."

Ext.4

In this extract, the young man expresses how helpful it was to have his mother at home at the end of the school day, so that he could talk to her about his stressful day and anxieties about school.

Mum: "Yeah he used to come home... in year eight every day he'd come home and talk to me for about half an hour and I think he needed that."

Ext.5

In the above extracts, sons see mothers as invaluable. Such comments are typical of those made by the young men in this research project. Implicit within this is vulnerability that the young men portray in coping in the social world. Their mothers have intuitively recognised their son's vulnerability and have protected them to ensure that they will not be harmed. The lionesses and lion cubs seem to me to be an accurate observation of this intimate relationship.

4.4.3.2 Friends and Support

In this extract the young man describes what a friend is to him:

J: "Well I've got lots of friends and... well the people on the bus can be nice sometimes and... and at other times they can be darn right annoying."

Ken: "So why are they friends then, why would you... why are they friends, what makes you feel they're friends?"

J: "Are you asking me what a friend means to me?"

"Someone that just being them, I'm not particular about them except there are things that... that I wouldn't be able to call them friends because of certain reasons."

Ext.10

Here, the young man talks about his relationship with other adults, particularly his teachers, with whom he struck up positive relationships:

Alex: "I tend to get on with the teachers at school more than I get on with the other pupils, I think because the teachers tend to be more well mature, that... not that I... not... I mean I don't mean that in a... what I mean is... oh well it's a bit hard to explain..."

Delia: "The kids don't understand you do they?"

"He's got a proper friend now, this year is the first year he's had a proper friend."

Ext.11

Here, the young man speaks very positively about relationships and school. He affectionately refers to a place in the playground which harbours his friends.

Ben: "Um I just like the environment and being around people and I get on really well with the teachers as well as the students now, so a lot more than what I used to."

"Yes um I have one area that is in the playground at the moment it's full up with all my friends."

“Um my mate Jake who lives around the corner and I’ve got um another friend Jack who lives up the heath way and but I go to the club with Jack as well.”

Ext.13

This young man talks about his close friends who understand him:

Callum: “Well I guess my really close friends are my friends because they understand that I’m not the same as well normal people , they know why I get agitated easily and all that so they tend to um you know just...”

Rachel: “Ignore you [laughs].”

Ext.14

In this extract the young man talks about his first experiences of making a friend and how meaningful it was for him to be able to do so:

Tim: “Yeah, yeah I did... I did make particularly musical friends as well um a guy I knew who I still go to college with was Alfie who I was friends with for years and years um back and you know, I can always just remember just having really being joyful about the fact that I managed to make a connection with somebody in the end um although you know it took a lot of time for it to finally sort of happen but you know I just, you know I was overjoyed with that and yeah.”

Ext.21

This man talks about not having friends his age and interacting with older people who were similar to him.

Phillip: "Yeah I didn't socialise with anybody my age, I didn't do anything like that."

"Oh it was alright, I had a few friends. You pick your close friends don't you and you stick with them but I found it really hard to manage friends throughout school, a lot of them are older than my age group and they were...well a lot of them were adults weren't they? People I used to hang around with work with and socialise with but..."

Ext.20

In this extract the young man is unclear about what a girlfriend is:

Tim: "Well I don't know, I wouldn't say I've ever been the smoothest but um, no I... no uh I've had one..."

"I think my parents have always teased me about things like that so I've never... never taken too kindly bring a woman home. Yeah I've had one or two girlfriends if you can call a couple of days a girlfriend."

Ext.9

In this extract the young man uses the term 'friendly stranger' to describe acquaintances:

Alex: "I mean I say hello to them if I um pass them in the corridors but I'm just not friends with them anymore, not just you know just friendly strangers as it were."

Ext.12

In this next extract the young man talks about fellow students being aware and curious of his condition and becoming friends as a result of this curiosity:

Jethro: "Yes well they're sort of vaguely aware of it sort of anyway, sort of you know I think they know I'm on the autistic spectrum or whatever and sort of reading about sort of or whatever I mean it was like I'm not quite sure they've twigged that I'm the same person who I was back then but the time will come."

Ext.22

The above extracts highlight how confusing it is for the young men in understanding their relationships with peers and how this has been a source of anxiety and frustration for them in developing friendships.

4.5 Summary of Chapter

This chapter has presented the three themes and eight subthemes resulting from the data analysis. In the first theme the process of obtaining the diagnosis of AS firstly from the parents' experiences, in which the views of mothers (lionesses) was privileged. The experiences of fathers were included to contrast the journey that mothers have experienced. This was followed by focusing upon how the diagnosis has impacted on the family in respect of

coming to terms with it and the support the family experienced. The second theme generated focused on the findings of how the diagnosis has impacted on the family's journey to get the young man's needs recognised by the LEA and focused on two areas, including the fight to get their son's needs legally recognised through the process of obtaining a Statement and how schools view the young men, and crucially how the young men were supported in school. In the third theme the views of the young men (lion cubs) were considered, including their view of what a diagnosis of AS means to them; their views on educational outcomes and on relationships.

The next chapter will discuss the implications of the findings of the project research questions.

5. DISCUSSION

5.1 Introduction

This chapter presents a discussion of the research questions in line with findings outlined in the previous chapter and with reference to Chapter 2, the Literature Review. In sum, through the process of TA outlined in the previous chapter, three themes and eight sub-themes were generated from the data. These encapsulated the parents' experience of obtaining a diagnosis, the impact of diagnosis on the family and the perspectives of the young men involved. This chapter focuses on a discussion of the findings with regard to the research questions. A critique of the methodology will then follow and the chapter will be concluded with my observations of lessons learnt, ways forward and reflections of this research study.

This discussion will now focus on an analysis of the research questions.

5.2 Research Questions

In order to report on the findings from the young men and mother's interviews, the next section is organised into four parts, which relate to the main research question:

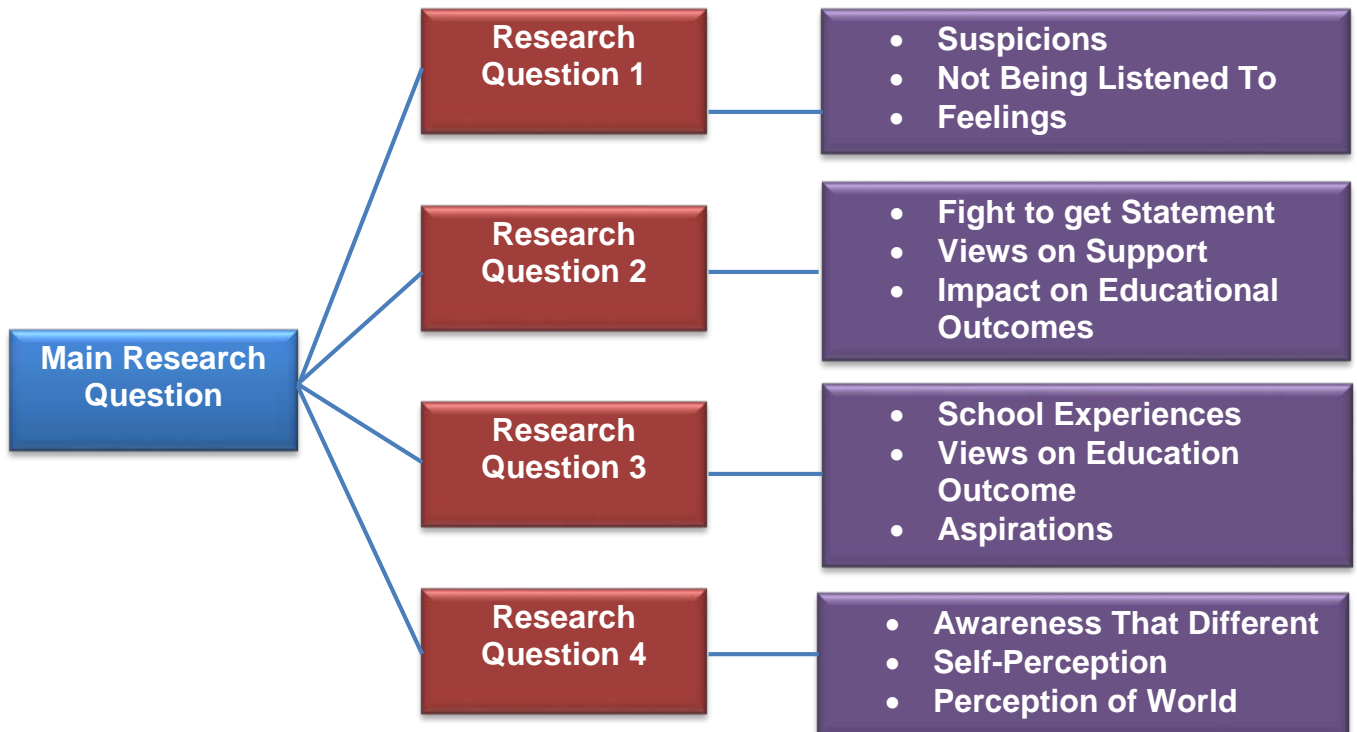
"How has the diagnosis of Asperger Syndrome impacted on the educational experiences of young men?"

Four sub-questions were generated in order to explore the research question:

1. What are mother's experiences of having to obtain a diagnosis of AS for their sons?
2. What are the mother's experiences of their son's education following the diagnosis?
3. What are young men's experiences of their education following the diagnosis of AS?
4. What are young men's experiences of having a diagnosis of AS?

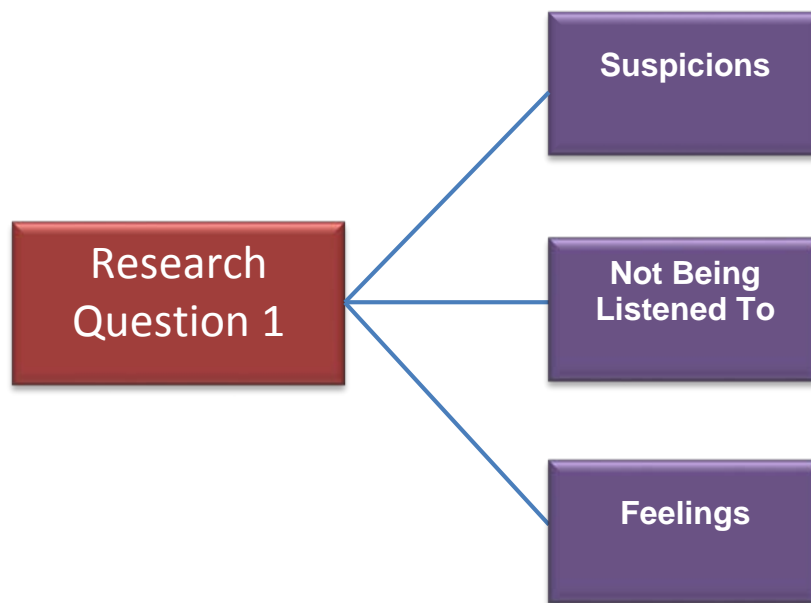
The themes from which the sub-research questions were analysed are highlighted in the following diagram:

Figure 5.1 – Main Research Questions



5.2.1 Research Question 1 - What are Mother's Experiences of Having to Obtain a Diagnosis of AS for their Sons?

Figure 5.2 - Research Question 1



5.2.1.1 Mother's Suspensions of AS

The findings clearly say something about mother's intuitive nature in recognising that something was not quite right in their son's development and, although not aware of the condition, realised that further medical investigations were required. This would become more apparent when their sons started pre-school provision and it became much clearer that their sons were different to other children. As a consequence of this, mothers became concerned that their sons would need protection and support in the school environment and, with this realisation in mind, sought out more information as to what support was available in nurseries.

5.2.1.2 Not Being Listened To

Mothers continually expressed their concerns at not being listened to by a range of professionals who constantly reminded them that they, as professionals, knew best. Mothers commonly reported that the professionals advised that their sons were just being naughty and this was mainly due to attention seeking behaviours. When questioned by mothers about alternative explanations, the professionals were dismissive of mothers view, implying that they knew best. Mothers also talked about being dismissed by professionals as overprotective and unduly concerned parents. The mothers were told that it was their fault that their sons were the way they were and that, as parents, they needed to consider their parenting skills as a major factor in how their sons were behaving. The concept of the 'refrigerated parent' is very evident here (Kanner 1974):

It is clear that mothers were led to believe it was their incapacity to nurture their sons that was the source of the issues they were experiencing with their son's behaviours and this proved to be extremely debilitating for many of the participants. Similar findings were reported by Sansostini, Lavik & Sansostini (2012) who found that professionals did not appreciate or share the parental concerns and seemed unwilling to take account of parental information. Being perceived as an equal partner in the process of understanding their son's needs did not occur to most of the mothers in the research study and highlights an issue as to who is the expert. This analysis of early childhood experiences would suggest that mothers are the most likely experts. Leblanc & Boyer (2014) discussed with parents the issue of who is to be seen as an

expert and concluded that satisfied parents tended to view supporting professionals as having specialist expertise. Parents expressing more negative feelings argued that they were expertly knowledgeable about their own child and should have a greater say in decision making. This research indicates that mothers were the most effective advocates for their sons and therefore it is important that their views are seen as a central aspect in their son's planning.

5.2.1.3 Feelings Regarding the Journey to Gain Diagnosis for Son

Linked to the previous theme 'not being listened to' was the emotional journey of the mothers in which a range of feelings were articulated about how it felt for them not being heard, being judged and being blamed for their son's unusual behaviours. Their emotional journey to get a diagnosis (thought, at the time to be the way forward to gain additional resources) and feelings experienced once the diagnosis was obtained ranged from relief to immense guilt and anxiety that a lifelong condition had been determined. In part, this section is linked to the adversarial role of this group of mothers but the focus here is much more on the internal values and beliefs that mothers held and which impacted on their abilities to fight for their son's rights through practical means. Mothers in this research talked about feelings of inadequacy in not being able to manage their son's unusual behaviours and of being judged by other mothers as having poor parenting skills. However, implicit within this was mother's feelings that they were nurturing their sons who did not have the prerequisite skills to socialise appropriately. This became a source of anguish for mothers. Sansostini, Lavik & Sansostini (2012) report on how ceasing

going out on recreational visits due to anxieties about the likely reactions of other people to the children's' behaviour was prevalent with the parents in their study. Further, that most friendships were with the families of other children with ASD. This was supported by the experiences of mothers in this research.

Following the diagnosis of AS, an immense sense of relief was experienced by mothers who had constantly been told that it was their fault that their child had behaved inappropriately. The feeling of tension and anger that they were 'banging their heads against a brick wall' had subsided and a general optimism arose that now there was a 'light at the end of a tunnel'. However, despite being relieved that they were not to blame for son's unusual and challenging behaviours, the realisation that their sons had a lifelong condition which would not go away or be treated in traditional medical terms (i.e. that a 'pill' could be taken to cure) was very hard-hitting for many mothers in the research.

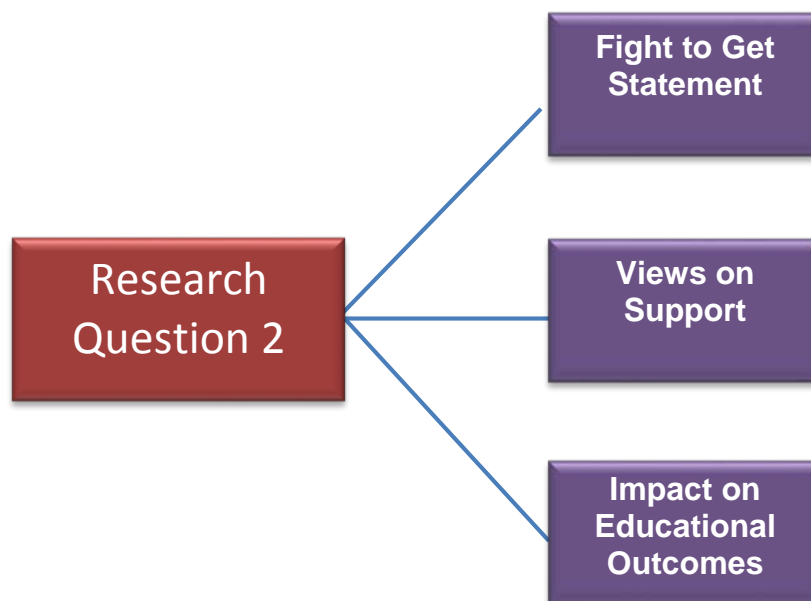
Once a diagnosis was made, real concern surfaced about how best to support their sons, not just immediately but in the future. Implicit within this was deep anxiety and feelings ranging from that of the diagnosis being devastating for the future to one of sons being able to cope with support. One of the main feelings reported was that of pessimism, that the son's life had ended and they would never be able to achieve what others could do due their inability to interact and socialise appropriately. Despite this, the mothers maintained a determined stance to research the condition and many joined the local

support group as well as the NAS, which fuelled their quest to gain the right support and recognition of their son's needs. The more general view was that their sons should not miss out on opportunities because of their condition and, in order to do so, mothers took on an additional advocacy and activist role. Ryan & Runswick-Cole (2009) found that the role of advocate on behalf of their children diagnosed with AS is one that many parents will adopt. The Stoner & Stoner (2014) study investigating the impact of a diagnosis of ASD on the parents' role found that they became heavily involved in exploring the various educational, psychological or physical needs of the children. Further, they reported that parents generally found support from their partners, other members of the extended family and from parent groups.

In sum, the analysis highlights that the period prior to and immediately after the diagnosis of AS, when parents and mothers in particular are striving to understand the implications and to identify available services, is likely to be especially challenging and marked by anxieties as well as some sense of loss and isolation. It is important at this juncture to point out that the experiences of dads were not the focus of this research and the findings of this research have indicated that they have a lot to say about how the diagnosis has impacted on them and their roles as fathers in supporting mothers in their quest to ensure that their son's needs were addressed.

5.2.2 Research Question 2 – Mother’s Experiences of Educational Outcomes Following Son’s Diagnosis of AS

Figure 5.3 – Research Question 2



Once the diagnosis was obtained, appropriate educational recognition and support remained a crucial area to pursue. The analysis identified a range of themes provided by mothers regarding their experiences of having gained the diagnosis of AS, using this to request that a Statutory Assessment of SEN be undertaken by the LEA so that appropriate support could be provided in the schools that their sons attended. The time taken to obtain a Statement of SEN also proved to be very significant and of much concern to all families involved in this research project. Their concerns did not end with the Statement being issued, as further complications often arose regarding the appropriate specialist support required. Support for mothers regarding their journey to get

their son's needs recognised also proved to be an issue of considerable concern.

The main subthemes identified in this research question were as follows:

5.2.2.1 Fight to Get Statement of SEN

There were many examples of mothers having to pursue legal support and advice to get their son's needs recognised. Linked to this was the financial implication of pursuing the appropriate support package to meet her son's needs. Having got recognition that the LEA deemed a Statutory Assessment appropriate, there still remained issues related to the time involved in getting a Statement of SEN issued.

Mothers communicated their feelings about the extreme difficulty experienced in obtaining the right support and legal recognition of their son's condition and special educational needs via a Statement of SEN. Mothers talked of an 'enduring battle', which on many occasions took years, to ensure that their son's needs were recognised and appropriate support provided. However, issues regarding support continued to be a main source of concern as their sons progressed in their education. Stoner & Stoner (2014) study highlights how once battled to obtain a diagnosis of Asperger Syndrome mothers then took further their role as advocates to fight for their children's educational wellbeing and implicit within this was a need to normalise their child. This was also emphasised in Lasser and Corley (2008) and Ryan & Runswick – Cole (2009) studies in which mothers were acknowledged to be the main

advocates fighting to ensure that a statement of SEN was obtained to provide the correct support for their child in order to ensure that they would not be at a disadvantage to their peers.

5.2.2.2 Views on Support

On analysis of the data it was clear that, despite managing to secure the Statement of SEN and having quantified the areas requiring support, there remained a fundamental issue of appropriately trained and experienced specialist support. The tendency was for the school to provide support from support assistants who had no experience of working with children with AS and who, unwittingly, were often a source of anxiety for the young men due to inappropriate understanding of their needs. Once again, as with pursuing the diagnosis, there existed a sense of not being listened to as, having obtained the Statement of SEN and fighting to ensure that the young men's' needs were acknowledged in the Statement, there remained an issue of what happened in practice. This proved to be frustrating for mothers and the young men and was a concern reported by most participants in the research study. Linked to this was the concern that the school knew best and inappropriate training was being provided to assist them in meeting the young men's needs.

Mothers talked about support being withdrawn without their knowledge or consent and, having challenged this, being told that the school knew best and this was in order to promote independence in their sons. They talked about how this created more anxieties in their sons, which resulted in challenging behaviours at home. There is something here about the power of control that

the school has in deciding, without consultation, what was appropriate in meeting the young mans' needs. The decision to withdraw or reduce support was, and to a certain extent still is, considered to be good practice in supporting the developing independence in the young men concerned. Another form of changing support involved variation in personnel in order to maximise the child's ability to interact with a range of support workers. Many of the mothers interviewed in this research study expressed their concerns about the impact such practises had and how this affected their lives at home. The terms 'backlash' and 'if it's not broken, why fix it' is emotional language used by parents to highlight their distress at not being involved in decisions regarding their son's education and in particular support arrangements. The heterogeneity of children identified with ASD in mainstream schools must be recognised when educational provision is planned or reviewed. Whitaker (2007) highlighted that where satisfaction was high, parents frequently made specific references to good communication with staff, involving a willingness to listen to parental concerns and to tap into parental knowledge and experience when seeking to deal effectively with issues arising at school. Among parents generally dissatisfied, communication was commonly a source of concern. Robert, Leblanc & Boyer (2014) research on parent's experiences of support highlighted the positive aspects including parents being informed and involved in their child's support. However negative aspects included change in support staff and not being consulted as equal partners in the decision making process. Whitaker's (2007) research highlighted parental dissatisfaction about support provided including limited understanding amongst support staff to meet their children's needs and the need for

consistent communication between home and school to promote good models of support. In contrast, Alexander et al (2005) reported that parents highlighted good communication, consistent support and the feeling that everyone was moving in the same direction. This would seem to me as an excellent model of effective practice in schools and was born out in parts of the participant's experiences. The views of the students as reported in Tobias (2009) study echo this view.

5.2.2.3 Impact on Educational Outcomes

Here, many mothers talked about the school's ability to meet their son's social and communication needs rather than focusing on educational attainments. Mothers highlighted the need to provide the right training for staff working with their sons to access the learning environment. The impact of being excluded was raised by mothers as a main concern regarding their sons achieving at school. Mothers also identified issues they considered priorities for positive educational outcomes that schools needed to address, including more emphasis on developing their son's social, communication and relationships skills. Mothers also felt that there was a need for more discussion with the young men about their diagnosis and the problems that it produced for them as teenagers. Alexander et al (2005) found that parents felt positive educational outcomes involved schools offering a flexible curriculum covering a variety of provision (from full-time in a specialist base to inclusion within mainstream), adjusted according to the pupils' needs; a two-way flow of information with parents (daily diaries, planners, regular meetings, personal

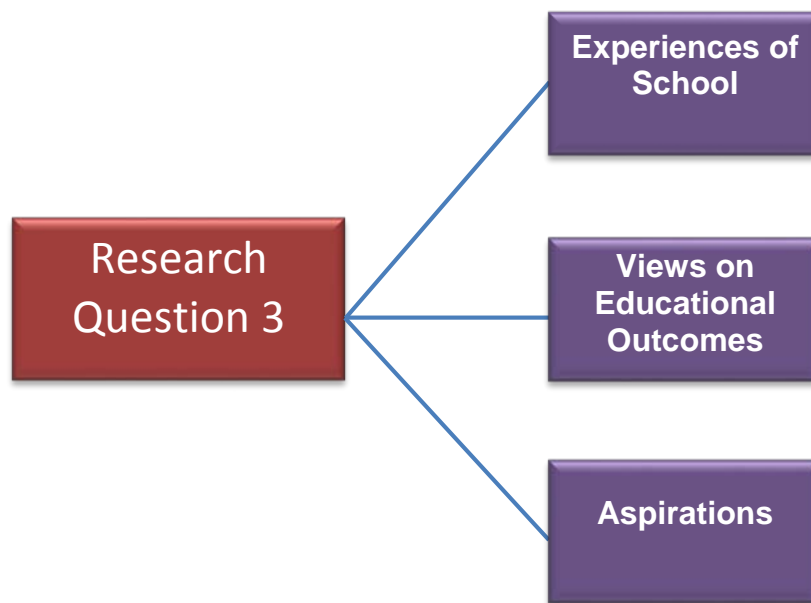
contact, phone calls, letters, parent's nights, reports) and a link person in school who knew the child very well.

'Constructing normalcy' is a term used by Lasser and Corley (2008) to refer to attempts by parents to create some meaning out of their circumstances and to establish the best environments and arrangements for their children diagnosed with AS. Mothers in this research study often commented on the difficulties arising from their sons with AS appearing 'entirely normal' to other people, so that problem behaviour is unexpected and possibly regarded as deviant or the result of parental deficiencies. Striving to ensure that their son's needs were being met was mother's way of ensuring that their sons were attaining the best educational outcomes alongside their peers.

The implication from these findings was that unless the appropriate considerations and differentiations were made, the young men would become disaffected and switch off from attending school.

5.2.3 Research Question 3 - What are the Young Men's Experiences of their Education following the Diagnosis of AS?

Figure 5.3 – Research Question 3



This section focuses on research question 3, young men's view of their education following the diagnosis and encompasses three sub-themes. Analysis of this research question has been drawn from the original theme 'young man's view'.

5.2.3.1 Experiences of School

Young men had many contrasting experiences of school and their education prior to and following the diagnosis. Linked to this were the changes in their physical (puberty) and emotional (adolescence) development, which also proved to be a great source of frustration and anguish in their quest to

maintain positive relationships with their peers, who by now had become very alienating and dismissive of them.

The analysis highlighted the need to provide the right training in social skills. The tendency to assume that the young men knew what to do socially was an issue that schools needed to address if they were to provide positive experiences for the young men. The young men also talked about the environment and how being in familiar and supportive places helped them to relax and make friends.

Many of the young men became victims of bullying by their peers thinking that they were in positive friendships but in reality were being manipulated. The bullying manifested itself in a number of ways resulting in a variety of responses from the young men. The incidences of bullying occurred in a variety of settings, including open spaces such as the playground where much difficulty was experienced by the young men's understanding of the social rules. This often meant that the young men were the subjects of cajoling and being made to do things that could get them into trouble such as swearing in front of a teacher or making an inappropriate (e.g. sexual) remark to another pupil. A variety of responses also occurred when incidences of bullying were reported by the young men, from fighting back to completely withdrawing from the situation. It is important to note that the young men's view of bullying may have been a misperception on their part and highlights the need for support and training in understanding the nuances of friendships and relationships. This training should occur prior to attending secondary school where complex

relationship difficulties can occur and cause much distress and, as reported in this research project, impact greatly on educational outcomes.

Alexander et al's (2005) comprehensive study involved eliciting young people's views about what made their school an effective or 'good' experience for them. The findings indicated that pupils with AS thought the general help received in school was good and included support assistance, work being broken down, time to think and additional time to complete work; were complimentary about having access to the base in their schools which helped them relax, catch up with work and maintain friendships and had many positive things to say which related to peers being friendly, nice and reliable. In contrast to this, negative responses included being bullied for being different. Concerns also centred on the size of the school, the number of teachers and new pupils.

Crucially this research has highlighted the findings in Hill's (2014) study which advocated whilst it is of importance to look through an ASD lens; it is of greater importance to focus on the unique strengths, needs and interests of the individual young person. The current research supports this view and, by illustrating the importance of involving young men with AS in the planning of provision to meet their needs, they showed themselves to be insightful in reflecting on what they found helpful and what could further enhance their education.

5.2.3.2 Young Men's View on Educational Outcomes

A range of views emerged from the young men regarding their education following the diagnosis in terms of what was achieved academically and socially. The findings highlighted issues about the inclusive practices of schools as many of the young men reported they were being excluded because of difficulties in socially understanding the nuances of friendships, i.e. how to behave in what was considered an appropriate way in school. This had a significant impact on their emotional well-being. A sense of not being treated as an equal is evident here, although some examples of emerging friendships became apparent as an understanding of the young men's needs were recognised by peers, who could provide much support in times of need.

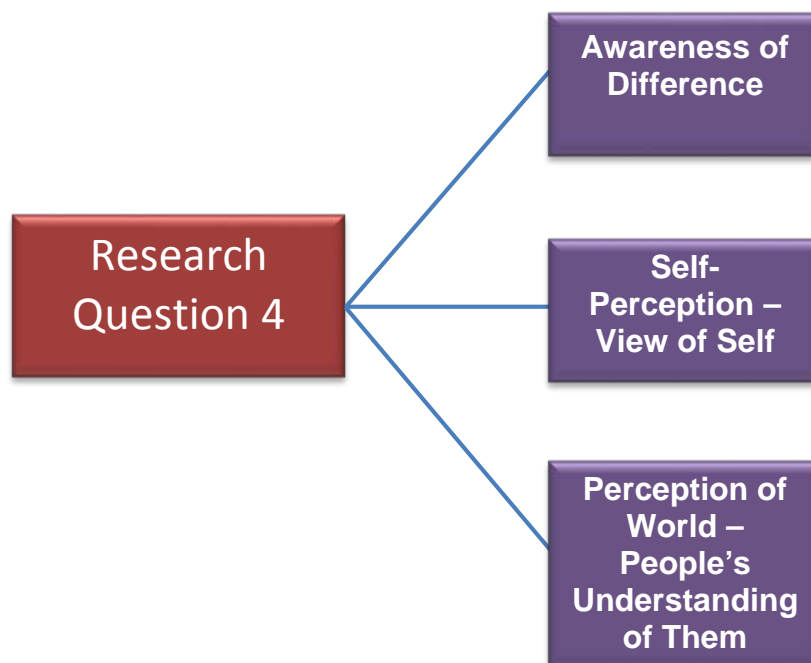
Tobias' study (2009) talks about increasing self-awareness by providing students diagnosed with AS a greater understanding of the condition and of fostering a sense of belonging and inclusion to limit the probability and anticipation of bullying, as well as increasing participation in social groupings. The current research supports this finding, as well as the need to foster the young men's independence by increasing their coping mechanisms and developing life skills, including direct teaching of social and life skills that will be critical in the post-school world. The findings also imply that support and provision should seek to fit the needs of the young men in this research rather than seeking to change or 'normalise' the students in order that they can somehow 'catch up' and be fitted to the existing and unmodified school arrangements.

5.2.3.3 Aspirations

Following the diagnosis a range of aspirations were depicted by these young men, which reflected their special interests and desire to succeed. Despite their social and communication difficulties and negative experiences of school, many of the young men interviewed for the research project held positive aspirations for the future. Although aware of their differences to peers and the acceptance that they would need to have support to enable them to read social situations, they were keen to pursue sources of motivation and interest into a productive vocation.

5.2.4 Research Question 4 Findings – What Are Young Men’s Experiences of Having a Diagnosis of AS?

Figure 5.4 – Research Question 4



This research question probes the young men's view of their differences to others; how this has impacted on the way they see themselves and people's understanding of them.

5.2.4.1 Awareness of Difference

The reports of the young men indicated that they became aware of their differences to others as they progressed into adolescence. They talked about not fully understanding the nature of their condition and gave a range of explanations as to what AS is, with the main conclusion being 'different to others'. They talked about the need for being accepted and about wanting to be valued for who they are and not to be judged negatively by others because of their atypical behaviours. Huws & Jones (2009) noted that there appears to be little evidence concerning the sharing of a diagnosis that may enable the young person concerned to make sense of the difficulties or differences experienced, thus providing reassurance and increasing self-esteem. Alternatively, the reaction may be very negative and the disclosure perceived psychologically and emotionally threatening (Shtayermman, 2009).

The implication from this study, supported in the current research, is that more needs to be done in sharing the diagnosis with young men in order to celebrate their strengths and not focus on deficits. I would agree with Milton's (2012) view that how ASD manifests itself can vary significantly between individuals and that this is socially mediated, via a process of constant interaction with changing environments. While problems with social and environmental aspects of the everyday world are common features of life for

people on the spectrum, 'being autistic' should not be framed purely through a deficit model lens.

5.2.4.2 Self-Perception – View of Self

The perception of having the diagnosis ranged from being positive, negative and apathetic in the research group and highlighted the need to provide more information regarding the condition to both parents and the young people concerned. As this group typically have difficulties expressing their emotions, the comments do not convey the inner feelings but more the thoughts about the condition in an analytical manner. In this regard the quality of the young men's responses must be appreciated to be less than that expected of those without the condition due to the limitations experienced by this group in expressing their feelings.

In this research the young men had varying views about the diagnosis, with some young men viewing themselves positively, particularly in their academic abilities, whilst others displayed a reluctance to believe or accept the diagnosis. The findings of this research study are in accordance with Huws & Jones (2009) findings that disclosure appeared to be associated with a range of reactions, but notably feelings of shock or disappointment and a reluctance to believe or accept the diagnosis. Further, those positive effects included a greater appreciation among other people of the difficulties and a reduction of negative treatment. References were made to some initial difficulty in accepting the diagnosis but a gradual learning to accept it. On the other hand, being identified with ASD was seen as having the potential to create new

opportunities, such as access to specialist support services. However, there were participants who maintained their reluctance to acknowledge the ASD and who talked of not wanting such a diagnosis and actively avoiding any information concerned with ASD.

The implications from these findings are that there needs to be a mechanism to alert young men of their differences in positive terms and, as Milton (2012) advocates, a move away from a medical deficit model. More needs to be done on exploring the social and cultural context of their diagnosis through an epistemological framework based on social constructivism.

5.2.4.3 Perception of the World – Peoples' Understanding of Them

In the analysis many of the young men described their way of dealing with the stressors of living in a social world and peoples' understanding of their behaviours. They talked about the need for structure and routine to assist them in making sense of their social world as well as the need for flexibility in all personnel that have a role in supporting the young men in a variety of social settings. Huws & Jones (2013) found that depictions of ASD predominantly centred on how participants felt they had developed socialisation skills and independence over time. Further, that although all participants described ASD as a type of disability, it was also perceived as being different and not as severe as other disabilities.

The implications from this research, and as with Huws & Jones (2013), is that these accounts seem to reflect how individuals compensate for differences

that they might view as stigmatising by avoiding what are known as 'by association' situations. Many of the young men in the research made references to others who were less able than them. The findings also concur with the McLaughlin & Rafferty (2014) study that all the young people felt AS had permanently impacted on how they viewed and acted upon the world. The realisation of the impact of their condition centred on comparison to, or reaction from, the rest of their peers. Academically this was seen to be a positive difference, in that it was often seen as the source of having more intelligence than their peers.

In the current research most of the young men described how they felt AS caused difficulty fitting in with their peer group and of AS being something of an unknown. This is commented on in the McLaughlin & Rafferty (2014) study as 'It' had no beginning point, there had never been a disruption to the self and so how could they fully understand 'it' without having experienced a typical alternative with which to compare. As with the McLaughlin & Rafferty (2014) study, most of the young men expressed having a desire to be treated like the rest of their peers, perhaps as a way to minimise the perceived impact of AS on their lives.

This research highlights the ability of young men with AS to comment on their diagnosis, communicate their needs and an explanation of their social wellbeing.

5.3.5 Overarching Research Question - “How has the Diagnosis of AS Impacted on the Educational Experiences of Young Men?”

The pursuit of the diagnosis by mothers has led to many positive outcomes for the young men, including recognition that the condition can impact on the social learning environment and that there needs to be much consideration regarding the school context to minimise the anxieties faced by young men who require structure, predictability and order to their day.

An enduring bond exists between the mothers and their sons and was apparent throughout the research; the conceptualisation of the lioness and lion cub seems apt to describe their relationship. As part of their natural instinct to protect their sons, the mothers in this research study, in recognition of their son’s needs, changed their lifestyles to become the main carers and advocates and most took on an activist role in challenging professionals and organisations who thought that they knew best.

Mothers spoke of a fight to ensure that their son’s educational needs were formally recognised through a Statement of SEN and that appropriate support was provided to meet their son’s needs. The journey proved to be a very emotional and draining one for mothers whose sons did not become fully aware of their differences to peers until secondary school, which coincided with puberty and adolescence. The young men talked about wanting to fit in and be normal, not singled out for special support. They talked about finding it difficult to interpret meaning to social situations and whether their friendships

were real. Much concern was expressed regarding bullying, mainly from peers but also from adults. They also had a range of views regarding their diagnosis and experienced some difficulty expressing how they felt about having this. However, they were able to describe some of the behaviours that had singled them out as different to peers some positive others negative.

Implicit within these findings is the need for all personnel working with young men with AS to have training in understanding the condition and how to elicit the views and aspirations of the young men who, despite having a range of positive and negative experiences, remained optimistic about their future, which was in contrast to some mothers in the study. The young men also talked about having their differences nurtured as strengths and to be able to explore their strengths rather than being forced to comply with the established curriculum. They also recognised that they needed training and support in understanding relationships and social situations and acknowledged that mothers had provided this support throughout their lives. Although academically able, there was a need for them to have more of a focus in school in developing the aforementioned skills. The young men talked about watching their peers, due to their concerns about not getting it right, when interacting with them. They also talked about having friends who understood them and shared the same interests.

Although optimistic about their future, there remained some uncertainty about how they would cope without their mother's support. The focus of the mother as 'the lioness' in ensuring that her son, 'the lion cub's', needs are addressed

is considered to be the most important aspect determined by the findings of this research and highlights the immense bond between mother and son. This is because of the role that mothers played in ensuring that the sons were correctly assessed and diagnosed so that appropriate support was provided to enable sons to progress educationally. Implicit within this was the mother's determination to fight to secure that their son's rights were addressed.

In the research project all sons spoke movingly of the support they had received from their mothers.

5.4 Critique of the Research Process

This section explores some key strengths of the research as well as identifying a number of limitations.

5.4.1 Strengths and Original Elements of the Research

In this research I would argue that, by engaging the mother's involvement as co-researchers in developing the interview schedule and participating in the interviews that was primarily aimed to elicit the voices of the young men, was a unique and very successful method through which a vast amount of invaluable data was generated from the young men about their experiences of having the diagnosis of AS and how the diagnosis had impacted on their education. The methodology unwittingly led to rich data being generated from mothers about their experiences, which greatly influenced me to incorporate their experiences in the research study.

The next section considers the limitations of this study and how certain variables may have influenced participants' accounts. It discusses possible implications for the study's findings and areas for further research.

5.4.2 Limitations of the Research Study

5.4.2.1 Data collection

Despite the strengths outlined above regarding the interviewing process being highly successful and facilitated by the cooperation of the mothers, I recognised that, as an interviewer and as an unfamiliar adult, it would have been more advantageous to have been able to interview the young men on more than one occasion. This would have facilitated a more relaxed approach based on familiarity in order to promote the ability of the young men to open up and respond to sensitive questions. On reflection there also existed a role in gaining participant validation for my interpretation of the data collected by inviting the young men and parents to comment on the interpretation of the data.

5.4.2.2 Participant Selection

I was keen to ascertain the views of young adolescent men about their experiences of having a diagnosis of AS and how this had impacted on their secondary educational experiences in recognition that this was an extremely challenging time for the young men coinciding with puberty and adolescence. Further, that little research has specifically targeted this group. However, I am mindful that the study's sample size and male-only composition prevents generalisation to the wider population of adolescents with AS.

5.4.2.3 Generalisation of Findings

Atieno (2009) argues that one of the disadvantages of using a qualitative research design is that the study's findings cannot be extended to wider populations. I am also mindful that the findings from this research is set in one country and, although it is possible there will be some shared significance and implications, there needs to be some caution of the potential impact in other settings. Therefore, the issue of the lack of generalisability of the findings was a result of the research design, which was chosen in the first place for its potential to produce intense descriptions. However, it is hoped practitioners may use the current study's findings to reflect on how to better support adolescents with AS.

5.4.2.4 Rigor and Credibility of the Research

What makes a successful and useful research is referred to as 'rigorousness' (Morse, Barrett, Mayan, Olson, and Spiers, 2002). Traditionally, reliability and validity are the criteria with which rigor and credibility are measured. The former are however usually associated with quantitative methods (Horsburgh, 2003). Creswell (2008) argues that reliability in qualitative research is concerned with uniformity of method across different studies and projects. Kirk and Miller (1986) encourage qualitative researchers to transparently record the procedure utilised in all stages of the study.

In this research I have endeavoured to clearly document the procedures used to recruit participants, collect data through interviews and analyse the data through thematic analysis in order to explore and discuss the findings in relation to the research question regarding participants' experiences.

With regards to the notion of 'validity', Guba and Lincoln (1981) argue that in qualitative research, the criterion of 'trustworthiness' is a better measure of a study's credibility. They argue that paradigm-specific criteria are necessary for addressing the issue of what they term as 'trustworthiness' of a study. Lincoln and Guba (1985) propose 'dependability', 'confirmability', 'credibility', and 'transferability' as measures of 'trustworthiness'.

'Confirmability' and 'dependability', are concerned with making sure that the study is clear as to how the conclusion was made, so that other researchers could see how I have come up with that particular conclusion (Merriam, 1998). To ensure 'confirmability', the steps taken throughout the study (Creswell and Miller, 2000) have been outlined in Chapter 2. They propose that an 'external audit' be applied, which is the method of having a researcher who is not involved in the research process; explore the process and outcomes of the study in order to evaluate the research's 'confirmability' and 'dependability'. In this research independent observers were my research support group colleagues who were involved in discussing the research procedures, checking on coding and theme extraction in data analysis and commenting of the research findings.

With regards to the issues of accuracy and transparency, I kept anonymised electronic records of the conversations gathered through the interviews. [Appendix 20]. This practice also encouraged methodological awareness and on-going reflexivity (Emerson & Frosh, 2004).

5.4.2.5 Reflections on the Ethics of the Research

Throughout the process of this study, a number of ethical issues relating to the participants' safety and to 'scholarly research' arose. Some of the ethical issues I encountered were how best to protect participant anonymity and ensure that I did not hurt their feelings, whilst also remaining true to the research. In this regard this included pseudonyms being used for participants' as well as any details that would identify them being removed from the background information. In order to minimise any distress the participants may have experienced as a result of the interviews, follow up telephone conversations were offered to discuss any concerns raised and to provide information regarding the outcome of the research. The participants were also provided with a video of the interview in order to comment further if they wished to. In the event all participants were happy with how the research had progressed and some even gave permission for the video transcripts to be shown as a means of highlighting the issues discovered in this research study.

5.4.2.6 Reflexivity

As a specialist in the field of ASD with over 20 years' experience working with young people with AS and their families, I was very aware that I could be considered to be overly familiar with the issues that this research posed and of the implications of incorporating my own solutions to the research questions. Thus as a researcher I needed to be considerate of the relationship between the participants and myself. Willig (2001) notes that the constructionist interviewer needs to be sensitive to the interpretative

procedures following the interviews. This meant that I needed to be aware, prior to data analysis, of the role of myself as interviewer and of any possible influences I may have had on the participants' responses.

Reflexivity in research is described by Hardy, Gregory and Ramjeet (2009) as:

"A process through which a person attempts to identify and recognize external and internal influences that can affect his or her understanding of a phenomenon under investigation" (p.11).

Sullivan (2002) argues that reflexivity is an important and essential element of qualitative research. Shaw (2010) also argues that it is essential for the researcher to be able to reflect on their research methods and analysis of data. In this research I have striven to sustain a reflexive attitude by being transparent about my experiences, cultural and professional background, as well as my values and assumptions which have influenced my epistemological position. I was also honest about my reflections and about how the research process influenced my perception of this study. This has been achieved by keeping a reflective diary which proved very useful when considering how the research developed and challenged my thinking as a researcher; having regular supervision discussions with my professional and academic tutors at the University of East London, my external supervisor and with colleagues who had conducted similar research for their doctorate studies.

5.4.2.7 Reflections about the Research Process

A number of studies, such as Alexander et al. (1989) and Milling-Kinard (1996), argue that researchers who are involved in gathering and reviewing case records of stressful and emotional experiences tend to be influenced considerably by the data gathered.

This was also the case in this study, as the whole research process did have a bearing on me. The interviews that I had with the mothers and sons were particularly emotional and moving. Furthermore, throughout the interviews I came into contact with some of the stress and the pain that the mothers went through as they recounted their journey of obtaining the diagnosis of AS for their sons and appropriate educational recognition and support. At the same time I also experienced the sense of advocacy, activism, love and support that they had towards their sons.

Reflecting on this research, I feel that my role has evolved throughout the process. My perspective as a researcher and the subject of the views of young men diagnosed with AS was shaped by my previous experiences as a LEA Specialist EP and consultant to many organisations including the NAS. Initially, when proposing this research, my position was that there was a need to elicit the views of young men regarding the diagnosis of AS and how this had impacted on their secondary educational experiences. I subsequently engaged the services of mothers in designing the interviews with their sons in order to ensure that they were comfortable with the interview questions. This meant the mothers were encouraged to be interviewed and questions were

designed to facilitate their journey of obtaining diagnosis and of their son's educational experiences. The subsequent interviews with the mothers (and occasionally fathers) yielded valuable data that led me to incorporate the parents', particularly mother's, experiences in the research.

The journey for me as a researcher has been an emancipation. I wanted to explore the social and cultural context of the young men's experiences of their diagnosis through an epistemological framework based on social constructionism. This greatly influenced the development of my research methodology in eliciting the young men's views. Although experienced in applying quantitative methods, I found that the use of qualitative analysis through TA suited my research stance and greatly influenced my understanding and knowledge of the views and experiences of young adolescent males diagnosed with AS. This experience has helped me to progress my professional practice and, in particular, facilitated my ability to consider how best to elicit the views of young people with AS. I am more confident as a researcher in applying qualitative methods and analysis in the future and am particularly keen to conduct further research into the views of girls diagnosed with AS and with Black Asian Minority Ethnic Groups.

5.5 Summary

The current chapter has focused on a discussion of the research questions. A critique of the research process and methodology was then presented. The chapter was concluded with my observations of lessons learnt, ways forward and reflections of this research study area.

6. CONCLUSION

The concluding chapter will include final discussions about the research study and highlight the distinctive contributions that have been made to the research and implications for the practice of Educational Psychology.

6.1 Distinctive Contribution

I have, over many years in professional practice, successfully developed ways of eliciting the views of the young person, often with parents and mostly with mothers present and this has proved to be very powerful in completing professional assessments. It was considered of great importance to develop more understanding of how young people diagnosed with AS viewed their diagnosis and how this impacted on their lives, particularly in their education. During what is considered by myself to be the first study of its kind, it explored mother's and their sons' experiences of gaining a diagnosis and what this journey meant in obtaining appropriate support to meet son's social, emotional and learning needs.

This was a small-scale qualitative and situated research study, which is highly relevant to current practice in Educational Psychology and for others working with children diagnosed with ASD/AS in schools. The research has produced a range of prevailing insights about the experience of having a diagnosis of AS and the impact of such on educational experiences for a group of adolescent men. The study has built upon the importance of understanding the relationship between sons and mothers. The analysis of the experiences

of the young men and their mothers enabled me to understand and appreciate how AS has had a significant impact on their lives.

Theoretically this research has provided evidence in support of Bowlby (1958), of the lasting attachment that existed between the mothers and sons which led to me to define the relationship in terms of 'the lioness' and 'lion cubs', with the lioness fighting to ensure that her cubs' needs were recognised through the diagnosis and support secured through the Statement of SEN. Similarly I was able to apply my knowledge of Attribution Theory (Heider, 1958) in recognising that the young men tended to relay their feelings through descriptions of their behaviours and that this appreciation was greatly informed by the psychological theories of AS alluded to in the introduction. I would argue that this falls in line with positive psychology (Seligman & Csikszentmihalyi, 2000) and in particular the positive aspirations the young men had in this research project.

6.2 Implications for Educational Psychology Practice

As the drive towards inclusive education continues, EPs will come across many pupils diagnosed with AS in their work within schools. It is important that all, and not just specialist EPs, are made aware of the implications for education of having this condition and are equipped with the training and knowledge of appropriate support and intervention.

An implication for EP practice is that of raising awareness of the needs of young people with AS in schools and providing training for teachers and

support staff. It is my opinion that EPs have a crucial role in providing this training as well as:

- Promoting appropriate interviewing techniques/questions to elicit the views of young people with AS.
- Advising on how best to involve them in reviewing their progress socially as well as academically.
- Promoting the involvement of parents.

EPs can act as advocates for young people in schools by including them in the programme of support and considering what techniques would be best employed to elicit their views. This may involve including them in reviews of progress and their aspirations for the future.

As EPs continue to have a key and varied role in LAs through their work with a number of different professionals in a variety of settings, it is important that they continue to develop their research skills in qualitative methodology to facilitate their ability to elicit the views of young people.

Future research could address the following questions generated from this study:

- How are EPs supporting parents once a diagnosis of AS has been made?
- How are EPs explaining the diagnosis to young men with AS?
- How are EPs supporting secondary aged young men diagnosed with AS?

- How are EPs ensuring that the local community are aware and informed about AS?
- How are EPs monitoring support and interventions of young people diagnosed with AS in secondary schools?
- How are EPs influencing LAs to develop policies and strategies for young people with AS?

I would also advocate that future studies could focus on schools identified as promoting positive learning experiences for young people with AS in the mainstream secondary school environment.

More research is required into the timing and process of sharing the diagnosis of ASD with the children and young people concerned to increase their potential involvement in decision making about care and interventions and in the development of Autism-specific services.

Finally, future research is needed to explore whether the experiences illustrated in this research by the young men are experienced more widely for female adolescents with AS and young people from Black, Asian and Minority Ethnic Groups.

6.3 Implications for Other Professionals

Professionals who work with families who have a child diagnosed with AS should be seeking the views of those diagnosed as well as those of the family. Individuals diagnosed with AS have voiced their discontent about not being

consulted about their views and, in this regard, all professionals should be aware of the potential needs and encompass the non-judgemental view of their condition. A multi professional approach should be incorporated in local diagnostic teams which should include specialist EPs and a holistic support plan should then be developed in consultation with all members of the family the voice of the child at the centre. This will mean that Professionals would benefit from training in working with families with AS and in developing skills in eliciting the voices of young men diagnosed with AS.

6.4 Final Comments

In the earlier chapters mention was made of the perception of parents, particularly mothers, being to blame for their child's ASD and that this was predominantly due to a lack of emotional support which led to theories such as Bettelheim's (1968) theory of the 'refrigerator mother'. This research has shown the exact opposite and has highlighted the immense bond between mothers and sons and of the crucial role that mothers have played in ensuring their sons needs have been addressed following the diagnosis of AS. The mothers have also played a crucial role in facilitating the voice of the young men to be heard in their understanding of the diagnosis of AS and of their educational experiences. Their involvement has enabled me, in line with the recent SEN legislation and the new SEN Code of Practice Guidelines (2014), to consider how best to ensure that this group can be involved in any decision making regarding their special educational needs.

In this regard, I would like to end with a quote that encapsulates the experiences depicted from the mothers and sons in this research:

“What a lioness was your mother among the lions! She lay down among them and reared her cubs. She brought up one of her cubs, and he became a strong lion.”

Ezekiel 19:2

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Mr Paul Curran
School of Psychology
Stratford

ETH/05/49/0

28 March 2006

Dear Mr Curran,

Research Ethics Committee: Application for the approval of an experimental programme involving human subjects: Pupil and Parent Perception of the impact of a diagnosis of Asperger Syndrome on Educational Outcomes. (K Greaves)

I advise that Members of the Research Ethics Committee have now approved the above application on the terms previously advised to you.

The Research Ethics Committee should be informed of any significant changes in the programme that take place after approval has been given. Examples of such changes include any change to the location, number of participants, scope, methodology or composition of investigative team. These examples are not exclusive and the person responsible for the programme must exercise proper judgement in determining what should be brought to the attention of the Committee.

Appended to this letter is the Interim Report form for which to report the progress of an approved programme involving human participants. I would be grateful if you could return this report to me before the end of your programme and use it to indicate any changes that may occur throughout. In accepting the terms previously advised to you I would be grateful if you could return the declaration form below, duly signed and dated, confirming that you will inform the committee of any changes to your approved programme.

Yours sincerely



Debbie Dada
Direct Line: 0208 223 2976
E-mail: d.dada@uel.ac.uk
Administrative Officer for Research



Research Ethics Committee: ETH/05/49/0

I hereby agree to inform the Research Ethics Committee of any changes to be made to the above approved programme and any adverse incidents that arise during the conduct of the programme.

Signed:  Date: 4/4/06
Please Print Name:

K. GREAVES

APPENDIX 2 :

LETTER TO PARTICIPANTS

Reference:	KG/Research
Phone:	020 8270 6900
Fax:	020 8270 6935
E-mail:	Ken.greaves@lbdd.gov.uk

Date:

Dear Parent/Carer,

“Pupil and Parent Perception of the impact of a diagnosis of Asperger Syndrome on Educational Outcomes.” Request for your support in research.

I am a Senior Specialist Educational Psychologist working in Barking and Dagenham.

I am writing to you as a parent or carer of a young person who has been diagnosed as having Aspergers Syndrome to ask for your and your child's help to participate in a research study that I am undertaking. This research has been endorsed by the London Borough of Barking and Dagenham, Dr Judith Gould, Principal, Centre for Social and Communication Disorders, National Autistic Society and Professor Sheila Wolfendale at the University of East London.

There is currently a great deal of interest in what pupils think about their education and how this has affected their views of the future. The pupil's "voice" is becoming an accepted way of evaluating educational provision and has indeed proven to be very useful in the recent Government legislation to promote the well-being of all children entitled "Every Child Matters".

The views of children who have been diagnosed as having a care, medical, educational or health need, is seen as crucial to this process.

As a Senior Specialist Educational Psychologist, I have a specific focus in ascertaining the views of children, young people and adults who have Autism and in this research I am particularly keen to elicit the views of young people aged between 11-16 about having a diagnosis of Aspergers Syndrome and how this has affected their education.

Your views are also an important consideration to the research and I am attaching a questionnaire to find out more about the diagnosis and your views about the education your child received. This should not take more than 45 minutes

I have also attached a consent form for you to complete if you wish for your child to be included in the research.

All the questionnaires will be collated by myself and will remain confidential.

A summary of the research findings, conclusions and recommendations will be sent to all participants.

It is my intention to tape record or video the follow up interviews. Please ensure that you have indicated on the consent form that you are happy for this to occur.

All records will be kept under lock and key and will only be used for research purposes.

I would be happy to answer any questions that you may have and can be contacted on:

Telephone Number: 0208 270 6900

E-mail: ken.greaves@lbbd.gov.uk

I would be most grateful if you would sign and return the attached consent slip with the completed questionnaire to the following address:-

Ken Greaves
Senior Specialist Educational Psychologist
Seabrook House
Shipton Close
Dagenham
Essex RM8 3QR

A stamped addressed envelope is provided to expedite matters.

Thank you for your help.

Yours sincerely,

Ken Greaves
Senior Specialist Educational Psychologist

APPENDIX 3: PARENT (MOTHER'S) CONSENT FORM

PARENT CONSENT FORM

“Pupil and Parent Perception of the impact of a diagnosis of Asperger Syndrome on Educational Outcomes.”

I give my permission for my child to participate in this research

(Name).....

(Address).....

.....

(DOB).....

(School).....

I consent to Audio () please tick
 Video () please tick

records to be gathered as part of this research in the knowledge that all information will remain confidential.

Signed:..... Date:.....
(Parent/Carer)

(Tel/Mobile).....

APPENDIX 4: PUPIL (SONS) CONSENT FORM

PUPIL CONSENT FORM

“Pupil and Parent Perception of the impact of a diagnosis of Asperger Syndrome on Educational Outcomes.”

I consent to being part of this research which will give me the opportunity to talk about my difficulties and how this has affected my education.

(Name).....

(Address).....

.....

(DOB).....

(School).....

I consent to Audio () please tick
 Video () please tick

I have been informed that all records gathered as part of this research will remain confidential.

Signed:..... Date:.....
(Pupil)

APPENDIX 5:

QUESTIONS SENT TO MOTHERS WITH INITIAL LETTER

1. What made you suspect something was wrong?
2. Who did you ask about your suspicions?
3. Did you find your worries were accepted?
4. Please outline below the experiences that you have had before reaching a diagnosis of Asperger Syndrome (e.g. who did your son see, what referrals were made, etc.)
5. When you were first told that your son was likely to have Asperger Syndrome?
6. Were you given any written information when you were told of your son son's difficulties? If no, would you have liked to have received this?
7. How did you tell your son/rest of family?
8. Did the person who told you about the diagnosis of Asperger Syndrome give you opportunities to contact him or her again to ask questions?
9. How did you feel about the information you were given at the time of the diagnosis?
10. Many parents feel the need for support after being told their son has a disability: Who did you turn to first for support? Who did you turn to first for information?
11. What do you think your greatest needs were when you were told about your son's disorder?
12. How did you try to get help for this?
13. Who did you find was most helpful? (Please give the profession)
14. In what way was this person particularly helpful?

15. Is there anything you would like to say about how you were prepared for a possible diagnosis?
16. Is there anything else you'd like to say about the period after you first learned that your son had Asperger Syndrome?
17. In your opinion, what would say are the important things that make a professional helpful? What do you find is particularly unhelpful?
18. What type of school does/did your son attend?
19. What impact if any has the diagnosis made on your son's education?
20. Overall, would you say you have more help or less help (or about the same help) since the diagnosis has been made?
21. Compared with the help you got before, would you say that you are more satisfied or less satisfied with the help you have received since your son started school - or do you feel about the same and your reasons why?
22. Who did most of the work in getting the help you and your son needed in the early days?
23. Did you feel that you did a lot of this yourself?
24. Who does this now?
25. Of all of the people you've been in contact with about your son, is there anyone that you would say has been the most helpful? (Please give their profession) In what way have they been the most helpful?
26. What do you feel are your son's greatest needs at present?
27. Is there anything else that you would like to say about the help you've had, or felt you needed, since your son was diagnosed?
28. Is there anything else that you feel has not been covered?

APPENDIX 6: SELECTED RESPONSES TO QUESTIONS BY MOTHERS

M = Mother

What made you suspect something was wrong?

- M6. I had 3 other children and this one was "different!!!" I didn't know what it was till he was 10, but I knew there was something.
- M8. His behaviour was challenging but I didn't feel he was being naughty; I thought he couldn't help it.

Who did you ask about your suspicions?

- M1. Class Teacher.
- M6. Doctors, school nurse, Social Services, C&FCS.

Did you find your worries were accepted?

- M2. Sometimes, not at school.
- M4 Dismissed as overprotective mother.

Please outline below the experiences that you have had before reaching a diagnosis of Asperger Syndrome (e.g. who did your child see, what referrals were made, etc.)

- M1. Age 9 - Educational Psychologist referral requested - turned down by school. Age 10 - GP referral to ADHD consultant - paid for privately and requested by us. Referral to CAMHS Psychiatrist for Occupational Therapy and monitoring of Ritalin following suicidal threats. LEA assessments by Clinical Psychologist, Educational Psychologist and Paediatrician for Statutory Statementing process. Age 12.10 - Referral to Specialist Diagnostic Centre by Psychiatrist at our request for diagnosis.
- M2. After 3/4 years of strategies for parenting, a child psychiatrist diagnosed at C&FCS. As he was hyperactive I thought ADHD they agreed hyperactivity but diagnosed Autism. I was told off by school for even mentioning labels like ADHD. Paediatrician Consultant saw him yearly or 6 monthly never diagnosed anything. It was difficult as he has acquired good language development.

When were you first told that your child was likely to have Asperger Syndrome?

- M6. About the same time, I was waiting for a GP appt for myself and was reading a magazine in the waiting room an article about Asperger. I recognised so much. I contacted the address at the end and that led to Elliot House.

Were you told that this diagnosis of Asperger Syndrome was definite?

- M2. Yes, but said Autistic Spectrum Disorder, did not mention Asperger's till later.

Were you given any written information when you were told of your child's difficulties? If no, would you have liked to have received this?

- M2. But I have since achieved lots of leaflet/books.

- M8. At time of definitive diagnosis.

How did you tell your child/rest of family?

- M1. We talked it all through as a family and I gave immediate family a copy of Tony Attwood's book to read.

- M6. Philip was told at the time - He found it a great relief that he was definitely "different" and not just BAD and WRONG!

Did the person who told you about the diagnosis of Asperger Syndrome give you opportunities to contact him or her again to ask questions?

- M2. Only via Family Therapist

- M4. Very much so.

If yes, how many and over how many months?

- M6. But there has always been contact by phone and better available and used even now.

- M7. Six months for about 3 or 4 weeks.

If no, would you have liked the opportunity to contact this professional and ask questions in follow-up meetings?

M5. No.

M8. Yes, although we did talk on the phone.

Many parents feel the need for support after being told their child has a disability: Who did you turn to first for support?

M4. Social Services/CAMHS.

M7. Autistic Society.

M10. Friends, family and teachers.

Who did you turn to first for information?

M2. P.A.C.T. and National Autistic Society for books.

M6. Specialist Diagnostic Centre - Autistic Society - Spectrum.

What do you think your greatest needs were when you were told about your child's disorder?

M2. He was having great difficulty at school as well as the home. He was excluded 5 times. I was worried about his education. The school viewed him as the "naughty child" of bad parents. The infants were a bit better and tried to teach him social skills.

M6. For people to listen to me, hear what I was saying and BELIEVE ME!

How did you try to get help for this?

M2. I went to "education" to have him statemented so he would receive support.

M10. I spoke to the head teacher at school and had support from the Educational Psychologist.

Who did you find was most helpful?

- M1. Our Educational Psychologist, GP and Consultant Psychiatrist.
- M2. Educational Psychologist and Clinical Nurse Specialist/Family Therapist.

In what way was this person particularly helpful?

- M2. Educational Psychologist visited school and home to make a report for statement as did the Family Therapist who also visited the school to advise and assure them of diagnosis. Later I met with lady from Education Inclusion/Specialist Service for Complex/Social and Communication Needs.
- M9. Prepared to listen as it is not helpful to offload the stress of dealing with a child with Asperger on your husband all the time.

Is there anything you would like to say about how you were prepared for a possible diagnosis?

- M3. I was lucky to meet a parent of a child with AS who prepared me for this being wrong with my child.
- M6. It was all down to my faith in my son and my parenting that I just kept looking, asking, reading etc.

Is there anything else you'd like to say about the period after you first learned that your child had Asperger Syndrome?

- M1. We are enormously relieved to know finally what his condition was and were able to better prepare and inform ourselves and him to be able to move on.
- M3. It was like grieving for expectations I had lost.
- M4. Social Services and LEAs should be much more supportive. Parents shouldn't have to face a monumental battle for help and support. Statementing process is ridiculous.
- M6. The elation at first to think we now knew what was going on and the despair and frustration that follows as nothing happened.

In your opinion, what would say are the important things that make a professional helpful?

- M8. Sympathy, understanding of how difficult it is for all family members living with someone with AS.
- M9. Ability to listen. Calm manner. Positive but not flippant. Not assuring that they know about your child until you have told them.
- M10. Caring, enough time allowed to ask questions. Listened to what was said to them. Helped to alleviate my feelings of guilt. Reassured me I was a good parent.

What do you find is particularly unhelpful?

- M1. To be ignored as parents by professionals who assume that we may not have the capacity to understand medical jargon etc and do not consult with us about our child in the way that we would have liked. This only happened particularly with educational assessments LEA led. Medical staffs were fantastic all round as was our Head Educational Psychologist.
- M4. Non-contact, Social Workers not qualified in diagnosing Asperger questioning his diagnosis. Parental ability being questioned.
- M5. Being made to feel that because you are not a doctor/professional that you don't know what's going on with your child.

What type of school does/did your child attend?

- M2. Jo Richardson Secondary School in the Additional Resources Provision. Previously always in a mainstream class.
- M4. None. Not given proper place in suitable school until aged 16. Permanently excluded few months later for behaviour.
- M6. Was mainstream until he was 12.5 - 6 weeks after his diagnosis he LEFT and never went back.

What impact if any has the diagnosis made on your child's education?

- M3. The Asperger affects all his life. Now has statement and has 25 hours one to one support in class. Cannot cope without this.

- M4. Huge - Couldn't cope in mainstream but no one listened to me and took necessary action for suitable placement until far too late in his education. Extremely frustrating, took 3 years to get placement agreed after virtual full time battle with LEA.
- M6. He has received very little education. Life Skills which he did need were ignored. He is self-taught extremely capable in what he knows and completely without awareness of money issues, food, time, budgeting, Inland Revenue etc. Simple he is a nightmare, bless him (and I do love him).

Overall, would you say you have more help or less help (or about the same help) since the diagnosis has been made?

- M2. I removed Joe from the 1st junior school and changed his school as the head teacher of his 1st junior school said he was the worst child he had come across in 30 years of teaching and if his bad behaviour continued in Sept. he would permanently exclude him. With that statement I felt I had no choice but to remove him for a new start in Year 4. The Head even phoned the new "Head" to warn him against my child. I was there when he received the call of the Head of the 2nd school. Fortunately gave him a chance.

Of all of the people you've been in contact with about your child, is there anyone that you would say has been the most helpful?

- M1. Occupational Therapist who diagnosed our son in the first place - our Educational Psychologist helping with diagnosis and Educational Psychologist supporting our application for specialist placement for our son - our GP for always being there for us.
- M9. Music Teacher, She channeled our son in his obsession for music. Was always patient and gave up a lot of time and energy to give him opportunities to perform.

What do you feel are your greatest needs at present?

- M4. Support for my son into adulthood e.g. supported housing and support worker to help with budgeting and individual living skills.
- M6. The peace of mind that comes with knowing that there is someone else that Philip feels he could trust and turn to for help 24 hrs a day. I know - but that is my wish!

Is there anything else that you would like to say about the help you've had, or felt you needed, since your child was born?

M3. If school in Reception year hadn't agreed with me that there was something wrong with my child I would never have fought for a diagnosis and my child would have been labelled disruptive.

M6. I think I have probably said enough. I don't feel I have had any help and Philip feels cheated and confused and now he is getting angry as well.

M7. It's been difficult having an intelligent child with Asperger. Help seems more available to less able children and we've had to fight more for the recognition of his difficulties. It took us two years to get a statement.

Is there anything else that you feel has not been covered?

M1. We were fortunate that our son was diagnosed at Eliot House through persistent requests by us as parents - eventually backed up by the psychiatrist. I feel it is a great shame that we had to go through traumatic years and our son threatening suicide before any interventions took place. We would have welcomed a visit to a specialist centre to help us cope once the diagnosis had been confirmed and perhaps to have been put in touch with other parents. It seems incredibly difficult to get access to a Clinical Psychologist - why is that?

M2. I feel the education system is inadequate and not suitable for Joseph or other children like him. If they are to be integrated into mainstream then every school needs knowledge and training plus extra people/resources for these children. Joe learns much better in a small group in a quiet place, not in a class of 30. Jo Richardson I believe is the only school in the Borough with 6 places for children with higher end spectrum Autism/Asperger but by going to PACT. There must be many more children in the Borough like this. Please provide more schools with "bases" like this. I believe in the near future there will be many more places desperately needed as more children seem to be having problems and diagnosed with Autism. I work as a SENCo in a preschool. I have tried to help several children with behavioural problems referring some to professionals. 3 young children I have worked with, together with parents, have traits of or diagnosed with Autism in the last 3 years. I have been careful not to label them myself, but supported parents if they have received a diagnosis from the appropriate professional. We have provided the children with the resources like a work station to begin their learning through "play tasks". I often wonder how they will cope a few years down the "line". What help is there for my son when he is an adult?

- M4. Although all agencies are now meant to work together, this has not been my experience. The lack of support has made things extremely difficult for the family, eventually leading to the family unit breaking down. Although I still support my son on a daily basis, I cannot look after him myself anymore. The lack of understanding from Social Services particularly is very difficult. They don't appreciate his vulnerability and needs at all, despite me taking them to complaint tribunal twice and the complaints being upheld.
- M6. Philip has never been taught life skills and this is now causing huge problems. He had no real academic needs that he couldn't meet through his own IQ. Now it appears the provision provided does not meet his needs, indeed is not ABLE to meet his needs..

APPENDIX 7: LETTER TO MOTHERS ARRANGING HOME VISIT INTERVIEW

	Reference:	KG/Research
	Phone:	020 8270 6900
Mrs R,	Fax:	020 8270 6935
	E-mail:	Ken.greaves@lbbd.gov.uk

Date:

Dear Janette,

“Pupil and Parent Perception of the impact of a diagnosis of Asperger Syndrome on Educational Outcomes.”

Thank you for completing the questionnaire and giving your consent to participate in this study. Following our recent telephone conversation I am writing to confirm that I will visit you and Alex on: **Wednesday 7th March at 3.30pm**, to conduct a follow up interview.

This will involve a discussion of the comments made in your responses to the questionnaire, a copy of which I have attached.

It will also involve an interview with Alex about his perceptions of the diagnosis and how this has affected his education and aspirations for the future.

Dependant on your consent the interview will either be tape recorded or videoed. All records will be kept under lock and key and will only be used for research purposes.

Thank you once again for agreeing to participate in this study and I look forward to our meeting.

Please do not hesitate to contact me if any further assistance is required.

Yours sincerely,

Ken Greaves
Senior Specialist Educational Psychologist

APPENDIX 8:

LETTER OF THANKS

	Reference:	KG/Research
	Phone:	020 8270 6900
Mr & Mrs R,	Fax:	020 8270 6935
Essex	E-mail:	ken.greaves@lbbd.gov.uk

Date:

Dear Mrs R and Alex,

“Pupil and Parent Perception of the impact of a diagnosis of Asperger Syndrome on Educational Outcomes.”

Thank you for the excellent interview carried out on **Wednesday 7th March at 3.30pm.**

As promised, please find enclosed a copy of the video which includes the discussion of the comments made in your responses to the questionnaire and Alex's perceptions of the diagnosis and how this has affected his education and aspirations for the future.

I am currently in the process of analysing all the interviews and will keep you informed of my findings.

Thank you once again for your participation in this study.

Please do not hesitate to contact me if I can be of any assistance.

Yours sincerely,

Ken Greaves
Senior Specialist Educational Psychologist

Telephone: 0208 270 6900
E-mail: ken.greaves@lbbd.gov.uk
Mobile: 0795 636 3701

APPENDIX 9: INTERVIEW SCHEDULE & QUESTIONS – MOTHERS

THE SCHEDULE

I will introduce myself and thank mother and son for taking time to enable me to have the opportunity to talk to them about their experiences of what having a diagnosis of Asperger syndrome means to them how this has affected sons education.

I will then explain the process to the interviews, which will involve interviewing mothers first about their experiences of having to obtain a diagnosis for the sons and how this has impacted on their son's education. I will then interview sons about what the diagnosis of Asperger syndrome means to them and how this has affected their education.

I will reassure mothers and sons that their identity will be kept confidential and that the answers to the questions will be included in the research, which will be used to help educational psychologists and others to understand how the impact of the diagnosis of Asperger syndrome has impacted on sons educational experiences. I will make it clear that they are free to ask any questions to clarify any aspect of the interview and that they have the right to decline to answer any of the questions or withdraw at any time from the interview.

Before beginning the interview , I will ensure that I have the mothers and sons consent to video and take record the interview, as well as explaining that the

recordings will be is transcribed. However, the videos will be used as a record of the interview. A copy of which will be sent to the family. I will reassure the family that all information will be kept secure under lock and key.

At the end of the interview, I will thank mothers and sons for their invaluable contribution and ask if any further information is required from myself and ensure that mothers and sons are not in any form of distress prior to reiterating the purpose of the interviews and the intention of the research. I will advise the family that they can contact me if required.

QUESTIONS FOR MOTHERS

1. When did you suspect something was wrong?
2. What was your son doing to cause concern?
3. What were you told by professionals?
4. Upon receiving the diagnosis, how did you feel?
5. Was the diagnosis of Asperger's syndrome explained to you or did you have find out yourself?
6. How has the diagnosis and impacted on the parenting of your son?
7. What effect has the diagnosis had on your sons education?
8. How did he get on when having to transfer to secondary school?
9. What type of support did he receive?
10. How has he progressed and starting secondary school?
11. How do you see his progression into adult hood?

APPENDIX 10: INTERVIEW QUESTIONS – SONS

Please refer to Appendix 9 for details of the interview schedule

QUESTIONS

1. Can you tell me about your experiences before you got the diagnosis of Asperger syndrome?
2. Do you know what Asperger syndrome is?
3. What does the diagnosis mean to you?
4. How are you getting on at school?
5. Do you have friends?
6. Do you have any difficulties?
7. Whatever support are you receiving?
8. How do you feel about the support?
9. What do you like about school?
10. What you like to do in the future?
11. Any other issues that you'd like to mention?

NAME: ALEX & JANETTE
LENGTH: 43:00

APPENDIX 11: THEMATIC ANALYSIS - MOTHER - STAGES I & 2

STAGE 1 -READING OF TRANSCRIPTION
STAGE 2- INITIAL CODING FOR THEMES

INTERVIEW WITH JANETTE – ALEX’S MOTHER

1. Ken: Today is the, what’s today’s date... it’s the 7 March and I’m um at
2. the home of Janette and I’m meeting her son Alex who has the.
3. condition known as Asperger’s Syndrome and it’s a follow-up to my
4. research with regards to the diagnosis of Asperger’s Syndrome and
5. perceptions of that and outcomes with regards to education. So hello
6. everybody.
7.
8. Janette: Hello
9.
10. Ken: Okay so if we can just start off perhaps with you Janette, it’s just um
11. really thanks for completing that detailed questionnaire. Um just really
12. when
13. did you suspect something was wrong?

INITIAL READING	THOUGHTS/ REFLECTIONS	CODES
As soon as Alex began to walk mother became aware that things were not right with Alex not seeking parental contact or affection	Must mention that did go through questions beforehand so that Alex was reassured of what questions to expect that mum was to help him answer the questions if he felt unsure.	

Parent suspicions
14-28

14. Janette: Um he would have been about three although from the moment he
15. started walking he was into everything, he was more than just a naughty
16. toddler, he got into some real scrapes didn't you?
17.
18. Alex: Erm not that I remember them.
19.
20. Janette: From the moment he got out of his cot my husband said there was
21. something wrong.
22.
23. Ken: Okay, what things was he doing, was he up to?
24.
25. Janette: Just into everything and didn't interact with you, he's always from
26. being a baby very independent, he didn't cry to be cuddled, he only want...
27. he cried if he was hungry or he was dirty, he never cried just for a cuddle,
28. he never wanted to be picked up or anything like that.
29.

2
A perception of affection
30-37

30. Alex: That's funny because I like... that's funny because I like... I like hugs.
31.
32. Janette: You do now like your hugs yeah.
33.
34. Alex: Oh yeah I've liked hugs ever since... as far as I can remember.
35.

INITIAL READING	THOUGHTS/ REFLECTIONS	CODES
		1 Parent suspicions 14-28
	Alex very much a part of the dialogue wanted to contribute about significant changes he had experienced	2 A perception of affection 30-37
Alex now likes hugs and sing surprise didn't when younger		

NAME: ALEX & JANETTE
 LENGTH: 43:00

36. Janette: Yeah.
 37.
 38. Ken: So... so...

39.
 3
 Role of professional – parents not being listened to
 4
 Transition – role of professionals
 40-49

40. Janette: I started off by going to the doctors and I got told that there was

41. nothing wrong with him it was me.
 42.
 43. Ken: Really?

INITIAL READING	THOUGHTS/ REFLECTIONS	CODES
		3 Role of professional – parents not being listened to 4 Transition – role of professionals 40-49
Mum initially blamed for expressing concerns about Alex's needs by her the GP. Problems continued in nursery and eventually at reception. Class teacher acknowledge that something was wrong. Alex is understanding the social rules. GP still blaming mother and stating that Alex was fine. It was mum's fault.	Impact on mother's feelings of guilt – her fault – too protective	
262		

LENGTH: 43:00

52.

53. Ken: Right.

54.

55. Janette: And he just didn't pick up, although the other kids picked up what

56. they were supposed to do, he didn't and then I went back to the doctors

57. with

58. that and the doctor again said no there wasn't anything wrong with him, he

59. was a fine strap... because he wasn't physically ill, he's a fine strapping

60. little

59. lad and it was me.

Role of professionals – this is what professionals can do for you 263

INITIAL READING	THOUGHTS/ REFLECTIONS	CODES

61. Ken: Again...
62.

63. Janette: Again, so I went to the clinic, took him to the clinic and saw this
64. school nurse who then referred him onto a consultant that way. And by the
65. end of... we were told towards the beginning of the academic year and by
66. the end of the academic year he'd been diagnosed as ADHD.
67.
68. Ken: Right.
69.

6
Mum the expert

7
Role of professionals – not listening

INITIAL READING	THOUGHTS/ REFLECTIONS	CODES
<p>Mum's persistence – took son to clinic to be seen by nurse who referred to consultant who diagnosed ADHD and prescribed medication.</p> <p>However mum not happy with diagnosis.</p> <p>Mum researched condition and became involved in a local ADHD support group were upon. She was advise that Alex was presenting more as a child with Asperger syndrome than ADHD</p>	<p>Mother's quest to have sons needs correctly identified.</p> <p>Very strong bond between mother and son – attachments and strong desire to protect get what's right for son.</p>	<p>professionals – this is what professionals can do for you 61-69</p>
<p>Medication didn't help. aced on special diet which helped. Moved away from behaving like a zombie.</p>	<p>Diet – more able now to tolerate dairy products. Gut and dietary issues prevalent within the</p>	<p>6 Mum the expert</p> <p>7 Role of professionals –</p>

8
Impact of diagnosis - medication
70- 87

70. Janette: But that didn't really fit. I have joined the ADHD support group and

71. what I was getting told he should be like didn't fit him.

72.

73. Ken: Like what things were you being told?

74.

75. Janette: Well he wasn't hyperactive, he always had purpose to what he did but

76. it didn't necessarily... we couldn't always see the purpose but he, if you

77. actually questioned him closely enough you would find out why he was

78. doing whatever he was doing because he was very independent, he didn't

79. ask how to do things he just got on with doing things himself. And the

80. person who ran the ADHD group had a son with Asperger's and when I

81. described Alex's behaviour she pointed out to me well actually that sounds

82. a lot more like Asperger's. So we went back to see the consultant the way

83. you do, we put... he was on Ritalin and that made him like a zombie.

84.

85. Ken: What just basically calmed... just slowed him right down?

86.

87. Janette: Yeah.

INITIAL READING	THOUGHTS/ REFLECTIONS	CODES
	condition. This has impact on behaviour.	not listening
		8 Impact of diagnosis - medication 70- 87
	Not sure about the ethics of giving a lesser diagnosis for fear of upsetting mother. Bella	

88.

89. Ken: Okay.

90.

9
Role of professional – impact of diagnosis

10
Mum the expert

11
Role of professionals – parents not being listened to

91- 104

INITIAL READING	THOUGHTS/ REFLECTIONS	CODES
Mum had to visit consultant on more than one occasion to be heard. Consultant then agreed with her view that sum was presenting with Asperger syndrome and changed diagnosis to Asperger syndrome.	had to raise the issue of Asperger syndrome before this was agreed. Other mothers have had similar experiences	
		9 Role of professional – impact of diagnosis
		10 Mum the expert
		11 Role of professionals – parents not being listened to

NAME: ALEX & JANETTE
LENGTH: 43:00

91. Janette: Yeah and we went back to see the consultant and I brought up that
92. I'd been told it might be Asperger's and she agreed with me.
93.
94. Ken: Oh right.
95.
96. Janette: And apparently she didn't like to say in the first place it was
97. Asperger's because she thought it was too much for parents to take
98. onboard, so she normally said ADHD first because that was a lesser
99. complaint and once parents had got used to that then introduce the idea of.
100. Asperger's.
101.
102. Ken: Really?
103.
104. Janette: This is what I was told; I wasn't the only one that was told ADHD
first.
105.

12
Strategies to help – diet

106-120

106. Ken: But um obviously there's an impact then with the Ritalin that he was
107. taking wasn't there?
108.
109. Janette: Yeah, well we stopped the Ritalin straight away. We tried to help
him
110. with dietary measures. He was doing a dairy free for a long time but he has
111. them now don't you? But...
112.
113. Alex: I remember I used... I remember I used to have to drink goat's milk
114. instead and that tasted horrible.
115.
116. Janette: Yeah, yeah.

INITIAL READING	THOUGHTS/ REFLECTIONS	CODES
		91- 104
		12 Strategies to help – diet 106-120

NAME: ALEX & JANETTE
LENGTH: 43:00

117.
118. Ken: So you don't have to have that kind of milk now then?
119.
120. Alex: No I don't like it.
121.

13
Co morbidity –
ADHD

14
Single-mindedness

122-151

122.
123. He's grown out of.
124.
125. Alex: I can get... I can get hyperactive some... I can get slightly like that
126. sometimes if um if physical... if physical (?) because I can sometimes get
127. Over excited, not hyperactive, over excited sometimes.
128.
129. Janette: But you know now yourself when you're getting over excited don't
130. you?
131.

268

INITIAL READING	THOUGHTS/ REFLECTIONS	CODES
Alex talks about being hyperactive relates this to being overexcited. Exhibit self-control and is and is more able to come himself down. When this occurs by taking timeout to read, which is one of his favourite hobbies.	Alex showed traits similar to others in this research – that of single-mindedness and independence. Is able to control his emotions and this is attributed to 'growing out of it.' By mother, but that is there something about how the Roman has facilitated this process, e.g. diet structure and understanding.	13 Co morbidity – ADHD 14 Single-mindedness 122-151

NAME: ALEX & JANETTE
LENGTH: 43:00

132. Alex: Yeah
133. Janette: And he normally will say I'm getting over excited, I'm going to go to
134. my room for a bit. And he goes and he chills out.
135.
136. Ken: Excellent.
137.
138. Janette: And you know he tends, he's still very independent and he doesn't
139. need entertaining, he entertains himself. He's never been a child who
140. needed entertaining as such because he likes his own company don't you?
141.
142. Alex: Erm.
143.
144. Janette: And he reads an awful lot.
145.
146. Ken: Erm, so um...
147.
148. Alex: I was actually reading when you knocked on the door mum.
149.
150.
151. Janette: Oh.
152.
153. Ken: Do you like books?
154.
155. Alex: Oh yeah.

269

INITIAL READING	THOUGHTS/ REFLECTIONS	CODES
Mums feelings of devastation of been told that Alex had Asperger's syndrome – that his life would never be normal, even though she knew that this condition was why he had.	Mums the need to protect the support Alex, 11, independent life was shattered by the stark realisation that Alex would not be	

NAME: ALEX & JANETTE
 LENGTH: 43:00

15
 Mums feelings – impact of diagnosis

16
 Self perception of needs

156-173

156. Ken: Okay we're going to ask you about that later on. Just going back to the
 157. diagnosis, you know when you found out how did it feel for you; I mean
 158. what were your feelings at that stage?
 159.
 160. Janette: It felt like my life had ended.
 161.
 162. Ken: Okay.
 163.
 164. Janette: Even though I already knew that it was Asperger's more or less ,
 165. came home and cried, and the way I saw it that was the end of it, he'd
 never
 166. have a normal life because I hadn't heard any stories of anybody with a

270

INITIAL READING	THOUGHTS/ REFLECTIONS	CODES
She was left to research the nature of the condition by herself and received no support from the relevant professionals.	“normal” like everybody else. Interestingly Alex disputes this. Issue noted parents having to find out for themselves about their sons conditions. This must have been the source of great anxiety and stress.	15 Mums feelings – impact of diagnosis 16 Self perception of needs 156-173
The only source of support came from the local support group for parents of children with autism	Mum talks about counselling required, i.e., someone to talk to about the struggle of having to come to terms with the nature of	

LENGTH: 43:00

172. Janette: No there isn't any such thing as normal.

[illegible]

APPENDIX 12 :THEMATIC ANALYSIS - SON - STAGES 1& 2

STAGE 1 -READING OF TRANSCRIPTION
STAGE 2- INITIAL CODING OFTHEMES

INTERVIEW WITH ALEX –SON

- 1. Alex: Can mum help me with some of the answers...
- 2. very patient Alex, thanks very much. Um I was going to ask you a few
- 3. questions because its um... mum’s just been you know (?) fantastic things
- 4. about how things have progressed. Um when you...
- 5.
- 6. Ken: Sorry?
- 7.
- 8. Alex: Some of the questions I might not know the entire answer...
- 9.
- 10. Ken: Well mum will help you...
- 11.
- 12. Alex: Can mum help with this?
- 13.
- 14. Ken: Absolutely yes she will, it’s just like how you have as well with her
- 15. when she’s mentioned things. Mum was talking about... you said

INITIAL READING

Alex keen to receive help from mother in case he doesn’t have the answer.

THOUGHTS/
REFLECTION
S

Alex was keen to have his mother involved in supporting him and was evident that a strong bond existed between them

CODES

16. things about when you were a child, um you've chipped in, is there anything
17. else you'd like to add about your experiences before you got the
18. diagnosis?
- 19.
- 44
Support for mum
- 45
A - Understanding of diagnosis
- 46
Impact of medication
- 669-684
20. Alex: I can't actually remember anything, I know it sounds daft but I just
21. can't remember. The only thing I can remember is possibly the tablets that I
22. was given (?while I was ADHD?) when they put (?) ADHD, my Asperger's
23. is
24. a form of ADHD.
25. Janette: No its not.
- 26.
27. Alex: Oh I thought that's what you said at first.
- 28.
29. Janette: No.
- 30.
31. Alex: Oh, no it isn't sorry, complete mistake. Right um no um all I
32. remember
33. is having to every day having to take these tablets that were shaped like
33. dinosaurs [laughs].

Alex remembers little about his past. Apart from taking tablets for ADHD, which confuses with Asperger syndrome.

Experiences of ADHD been a form of Asperger syndrome is a source of confusion for many families in this in this particular case, the family were led to believe that ADHD is a lesser form of Asperger syndrome

44
Support for mum

45
A - Understanding of diagnosis

46
Impact of medication

669-684

- 34.
35. Ken: Right [laughs].
- 36.
- 47
Strategies to support
686-697
37. Janette: Ah that was when we went and saw somebody and they put him on
38. all sorts of different vitamins and things that were supposed to help, we tried
39. everything you know the diets, the training. But the training is the one that
40. works.
- 41.
42. Alex: Oh yeah.
- 43.
44. Ken: What the actual...

Training is seen as the best intervention by Alex, a mother

A variety of interventions have been tried including:
medication
vitamins
diet
behaviour support

Mum uses a powerful statement of having to train her son like a pet (dog). Alex agrees that he needs training but challenges mum

47
Strategies to support
686-697

45.
46. Janette: You know training and (?)... that was how he was trained to get on
47. the bus, the same way you'll train a dog what to do, he was trained the
48. same way. (?).
49.
50. Alex: Not that I can't think for myself, I can't think...
51.
52. Janette: Oh you can think for yourself.
53.
54. Ken: So um do you remember, is there anything else about when... you
55. mentioned about that teacher, what about relationships with
56. other children or other adults or...?
57.

48
Relationships – friends

707-746

58. Alex: I tend to get on with the teachers at school more than I get on with

59. the other pupils, I think because the teachers tend to be more well matu

275

Alex tends to get on better with adults. Piers don't

perception states
that he is
developing his
own independent
skills can think for
himself

Alex will stay his
perception of
events. Even
though if it differs
from mum. Is
more open to
reason and tends
to stick to the
facts.

48
Relationships –
friends
707-746

NAME: ALEX & JANETTE

LENGTH: 43:00

60. that... not that I... not... I mean I don't mean that in a... what I mean is... oh
61. well it's a bit hard to explain...
62.
63. Janette: The kids don't understand you do they?
64.
65. Alex: Not all the time although I have got friends.
66.
67. Janette: Yeah you've got a friend there.
68.
69. Ken: You have got some friends (?).
70.
71. Janette: **He's got a proper friend now**, this year is the first year he's had a
72. proper friend.
73.
74. Ken: Excellent
75.
76. Alex: Well no he's been my friend ever since year 8.
77.
78. Janette: Yeah but he's more of a proper friend now, you ring each other up
79. and...
80.
81. Alex: Oh yeah.
82.
83. Janette: ...spend the break times and lunchtimes together.
84.
85. Alex: Oh yeah well we were doing that in year 8...
86.
87. Janette: So (?) number of years (?).
88.
89. Alex: We were doing it in year 8; we were doing it in year 8.

really understand him,
although he has some
friends and a particular
girlfriend. He spends more
time with.

90.
91. Janette: Were you?
92.
93. Alex: Yeah.
94.
95. Janette: You weren't ringing each other up.
96.
97. Alex: Oh no, no, no.

98.

49

A perception of diagnosis – what does it mean?

748-782

Alex is aware that Asperger syndrome is based on someone who discovered it.

Alex benefited from time to process questions and from mother clarifying questions to maximise his understanding in order to be able to respond appropriately.

Alex sees itself as different, but feels everyone is different.

Alex is aware that his brain works differently but doesn't have any real comments about having Asperger syndrome. His feelings suggest that he has always had the condition and doesn't know any

49

A perception of diagnosis – what does it mean?
748-782

NAME: ALEX & JANETTE

LENGTH: 43:00

99. Ken: So do you know what Asperger's Syndrome is then, what is it?
- 100.
101. Alex: Um it was... it was just... well I don't know if you could say discovered,
102. um I'll use that term for now, discovered for want of a better word if discover
103. isn't the proper word, um by someone whose surname was Asperger. Um I
104. know that I did something in year 5 on it um but...
- 105.
106. Janette: What does it mean to you?
- 107.
108. Alex: It just means I'm a bit different and everyone's a bit different in a way.
- 109.
110. Ken: Okay so how would you feel you're a bit different then Alex? What sort
111. of things, would you say that makes you a little bit different to the others?
- 112.
113. Alex: Uh I'm not entirely sure; I know that my brain works differently, that
114. was one thing yeah. It gets a bit complicated around then and I can't really
115. get my thoughts together on that bit, I'm not entirely sure.
- 116.
117. Janette: How does it make you feel?
- 118.
119. Alex: Well I just feel like I've always felt, I mean I've never... I've never
120. been non-Asperger's unless um... unless what they all say about
121. reincarnation's correct, I've never not been Asp... and even then I might

278

other ways of explaining what he has always had.
Uses the analogy of reincarnation to reinforce this point.

NAME: ALEX & JANETTE
LENGTH: 43:00

122. have been someone before with Asperger's...
123.
124. Janette: [Laughs].
125.
126. Alex: ...it could be like that but I mean I don't... I don't feel any way, I just
127. feel me.
128.
129. Ken: Okay.
130.
131. Alex: I don't know what anything else feels like because I've been like that
132. all my life.
133.

783-802 50
Impact of diagnosis on education

134. Ken: So do you have any particular types of difficulties that um that you
135. experience with classes just generally, just general life and school?
136.
137. Alex: I'm sorry, sorry there's something in my eye
138.
139. Janette: Do you have any difficulties generally with life in the school?
140.
141. Alex: Um...
142.
143. Janette: Take your hands away from your mouth.
144.
145. Alex: Sorry. Well yeah there is one and that's the Elton John calling.

50
Impact of
diagnosis on
education
783-802

146.
147. Janette: Yeah.
148.
149. Alex: That's because of the glasses of course um. It's a bit hard to ex... it's
a
150. bit hard for me to explain about the glasses because I get a bit muddled on
151. the fact, I think mum can tell you about them if you want to know about
152. them, but glasses help me.
153.

51

Strategy to help – intervention – impact on education

52

Relationships – bullying – strategy to cope

803-841

Alex talks about bullying
and strategies that is used
to deal with this

Alex is to where
special tinted
glasses to
process visual
information. This
has made him a
target of bullying
by his peers who
refer to him as
“Elton John.”

51

Strategy to
help –
intervention –
impact on
education

52

Relationships –
bullying –
strategy to
cope
803-841

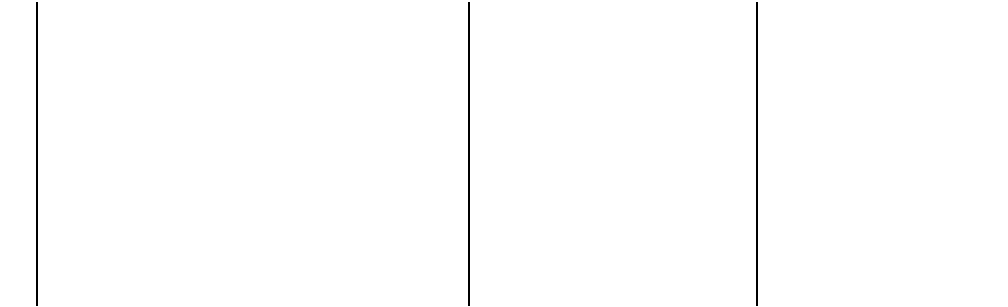
154. Janette: He wears the coloured lenses, he went for the colour test and
155. actually, they do make a difference; they help him walk in a straight line.
156.
157. Ken: Right.
158.
159. Janette: He doesn't veer off the way he used to but he does get call
names
160. at school because he's wearing dark coloured glasses.
161.
162. Alex: (?) Elton John.
163.

NAME: ALEX & JANETTE

LENGTH: 43:00

164. Janette: But they make such a difference to him, they help his
concentration
165. so much that he has to put up with the name calling.
166.
167. Alex: I thought the l... at the start of year 9 I decided on a way of backfiring
168. at it by if anyone ever said 'Elton' or something like that um I'd reply 'hello
169. idiot' just as if it was their name because that annoys them because they
170. have to be an idiot to think I'm Elton John because well I've seen pictures
of
171. him somewhere um my hair isn't as ginger, I mean I've got... apparently
I've
172. got ginger hair but its not that ginger and before it was dark, it was kind of
173. dark red glasses and its only until recently that I've had these bluish ones
174. and I think that men who wear... I think it's stupid when men or boys where
175. earrings, I think that's daft I must admit and I can't play the piano.
176.
177. Ken: Okay.
178.
179. Alex: But that's not entirely ob... of course that's not obvious because...
180.
181. Janette: Yeah so you've worked it out now, it doesn't bother you does it
when
182. they call you names.
183.
184. Alex: Yeah.
185.
186. Ken: Okay so you...
187.
188. Alex: There's not been a day when I haven't been called it.
189.
190. Ken: Oh so you get called it quite a bit do you?
191.
192. Alex: Yeah so it just starts to bounce off doesn't it?

NAME: ALEX & JANETTE
LENGTH: 43:00



APPENDIX 13: THEMATIC ANALYSIS STAGE 2 – SAMPLE OF CODED EXTRACTS FOR MOTHER – JANETTE

1

Mums suspicions

14-28

Janette: Um he would have been about three although from the moment he started walking he was into everything, he was more than just a naughty toddler, he got into some real scrapes didn't you?

Alex: Erm not that I remember them.

Janette: From the moment he got out of his cot my husband said there was something wrong.

Ken: Okay, what things was he doing, was he up to?

Janette: Just into everything and didn't interact with you, he's always from being a baby very independent, he didn't cry to be cuddled, he only want... he cried if he was hungry or he was dirty, he never cried just for a cuddle, he never wanted to be picked up or anything like that.

3

Mum not being listened to

40-49 and I got told that there was nothing wrong with him it was me.

Janette: I started off by going to the doctors and I got told that there was nothing wrong with him it was me.

Ken: Really?

Janette: Yeah it was my fault, I was an overprotective mum and there was nothing wrong and so by the time he'd got to school, when he was in... he went to the nursery, he didn't really fit in and there were concerns when he was in nursery and when he went into fulltime school the teacher took us to one side and said, I don't know what it is but there's something wrong with him. And she said you know it's seen as misbehaviour but he's not misbehaving but he just doesn't seem to understand the rules.

Ken: Right.

Janette: And he just didn't pick up, although the other kids picked up what they were supposed to do, he didn't and then I went back to the doctors with that and the doctor again said no there wasn't anything wrong with him, he was a fine strap... because he wasn't physically ill, he's a fine strapping little lad and it was me.

6 Mum the expert

70- 87

Janette: But that didn't really fit. I have joined the ADHD support group and what I was getting told he should be like didn't fit him.

Ken: Like what things were you being told?

Janette: Well he wasn't hyperactive, he always had purpose to what he did but

it didn't necessarily... we couldn't always see the purpose but he, if you actually questioned him closely enough you would find out why he was doing whatever he was doing because he was very independent, he didn't ask how to do things he just got on with doing things himself. And the

person who ran the ADHD group had a son with Asperger's and when I described Alex's behaviour she pointed out to me well actually that sounds a lot more like Asperger's. So we went back to see the consultant the way you do, we put... he was on Ritalin and that made him like a zombie.

Ken: What just basically calmed... just slowed him right down?

Janette: Yeah.

Ken: Okay.

10

Mum the expert

11

Mum not being listened to

91- 104

So she normally said ADHD first because that was a lesser complaint and once parents had got used to that then introduce the idea of Asperger's.

Janette: Yeah and we went back to see the consultant and I brought up that I'd been told it might be Asperger's and she agreed with me.

Ken: Oh right.

Janette: And apparently she didn't like to say in the first place it was Asperger's because she thought it was too much for parents to take on board, so she normally said ADHD first because that was a lesser complaint and once parents had got used to that then introduce the idea of Asperger's.

Ken: Really?

Janette: This is what I was told; I wasn't the only one that was told ADHD first.

15

Mums feelings – impact of diagnosis

156-173 It felt like my life had ended.

Ken: Okay we're going to ask you about that later on. Just going back to the diagnosis, you know when you found out how did it feel for you; I mean what were your feelings at that stage?

Janette: It felt like my life had ended.

Ken: Okay.

Janette: Even though I already knew that it was Asperger's more or less I came home and cried, and the way I saw it that was the end of it, he'd never have a normal life because I hadn't heard any stories of anybody with a child with Asperger's who then went on to have a normal life whatever normal is.

Alex: There's no such thing as normal.

Janette: No there isn't any such thing as normal.

18

Mum the expert - I had to find out myself

174-187

Ken: So how was that explained to you about what Asperger's is, did they explain it to you or did you just have to find out yourself?

Janette: I had to find out myself, I went to PACT and found out through PACT and I started to read about it, I read a lot of books on the subject. But. nobody, when he was diagnosed I was just told, yes that's it, it is Asperger's and bye bye, see you in six months.

Ken: Right

Janette: No there was no counselling or anything suggested and that was very hard. But I was fortunate that somebody had told me about the Asperger's support group, PACT. So consequently I went along there and then I started to learn more.

22

Mum the expert - impact of diagnosis

219-240 **it's like training a dog**

Ken: So you were more firm, any other things from your point of view, were there other aspects of your parenting that you changed?

Janette: Well we trained him, we started to train him rather than teach him because somebody said it's like training a dog. It sounds awful to say that's how you did it but we trained him how to do things and there wasn't any niceties of the pleases and the thank you's, I mean he learnt to say please and thank you and he didn't have a clue what it meant, he didn't have a clue what 'I'm sorry' meant but we taught him to say it; if you bump into somebody you say 'I'm sorry' and we didn't explain to him why because it was pointless, he couldn't get that part, but we taught him... the first thing we taught him was manners because it makes you accepted in the community if you have manners so he would say 'I'm sorry' for no reason at all. If somebody bumps into him he says 'I'm sorry'...

Alex: [Laughs].

Janette: Don't you?

Alex: Yeah.

Janette: Because we'd engrained it that much with the please and the thank you and...

29

Struggle to get support

386-396

Janette: Yeah and I actually found out through PACT that I could make an application for a statement and that's what I did when he went into year 2. And then it took a while, at first they said they wouldn't do it and then I said right well I'd go to appeal and about a fortnight before we were due to go to appeal we had a meeting at the school and they invited myself and my husband and suddenly decided they were going to statement him, or they were going to start the statement in process. So they started that and then by the time he'd gone into the beginning of year 3, it was a different school because he went over the road there and it's a separate infant and junior school, and just as he was moving up to the junior school he had 25 hours support. He's had 25 hours ever since.

Ken: And how's that been, has that been...?

Mums aspirations – feelings

639-647 **I feel quite positive because if he can be trained in the right way**

Ken: Um and I'm just thinking about what's um, what are your feelings with regards to the future for Alex or what would you like to see in place, you know what's... how do you see his progression into adulthood?

Janette: Now I feel quite positive because if he can be trained in the right way he could do anything; this is what I've learnt now. When I got the diagnosis I thought that's it, he lives with us for the rest of our lives and he'll end up in a home and now I think he'll be independent and have a career.

47

Strategies to support

686-697 the same way you'll train a dog what to do

Janette: Ah that was when we went and saw somebody and they put him on all sorts of different vitamins and things that were supposed to help, we tried everything you know the diets, the training. But the training is the one that works.

Alex: Oh yeah.

Ken: What the actual...

Janette: You know training and that was how he was trained to get on the bus, the same way you'll train a dog what to do, he was trained the same way.

Alex: Not that I can't think for myself, I can't think...

Janette: Oh you can think for yourself.

64

Mums feelings

Support – impact of diagnosis

1072-1081 if you meet parents who are newly diagnosed

Janette: Just that if you meet parents who are newly diagnosed tell them it isn't the end of everything, that it's amazing what can happen with the right support.

Ken: Yeah thank you very much, that's a very good point actually, it's an excellent point and it's...

Janette: It's something I wish somebody had told me when I got the diagnosis because I thought it was the end of the world and it's not. And they're such fascinating kids; it's just the beginning of the world.

APPENDIX 14: THEMATIC ANALYSIS STAGE 2 – SAMPLE OF CODED EXTRACTS FOR SON – ALEX

AWARENESS THAT DIFFERENT

A - Understanding of diagnosis

46

Impact of medication

669-684

Alex: I can't actually remember anything, I know it sounds daft but I just can't remember. The only thing I can remember is possibly the tablets that I was given while I was ADHD when they put ADHD, my Asperger's is a form of ADHD.

Janette: No its not.

Alex: Oh I thought that's what you said at first.

Janette: No.

Alex: Oh, no it isn't sorry, complete mistake. Right um no um all I remember is having to every day having to take these tablets that were shaped like dinosaurs [laughs].

Ken: Right [laughs].

49

A perception of diagnosis – what does it mean?

748-782

Ken: So do you know what Asperger's Syndrome is then, what is it?

Alex: Um it was... it was just... well I don't know if you could say discovered,

um I'll use that term for now, discovered for want of a better word if discover

isn't the proper word, um by someone whose surname was Asperger. Um I

know that I did something in year 5 on it um but...

Janette: What does it mean to you?

Alex: It just means I'm a bit different and everyone's a bit different in a way.

Ken: Okay so how would you feel you're a bit different then Alex? What sort of things, would you say that makes you a little bit different to the others?

Alex: Uh I'm not entirely sure; **I know that my brain works differently**, that was one thing yeah. It gets a bit complicated around then and I can't really get my thoughts together on that bit, I'm not entirely sure.

Janette: How does it make you feel?

Alex: Well I just feel like I've always felt, I mean I've never... I've never been non-Asperger's unless um... unless what they all say about reincarnation's correct, I've never not been Asp... and even then I might have been someone before with Asperger's...

Janette: [Laughs].

Alex: ...it could be like that but I mean I don't... I don't feel any way, I just feel me.

Ken: Okay.

Alex: I don't know what anything else feels like because I've been like that all my life.

58

A awareness of being different to peers

59

Sources of motivation – academic abilities

905-927

Ken: So what else, what do you like about school then Alex, what do you like about your school?

Alex: I'm not entirely... I'm not entirely sure, I like school but I'm not entirely sure what it is. Its definitely not... well apart from being with other people who are friendly with me, **I wouldn't say it's in the children.**

Ken: Right.

Alex: Apart from...

Janette: You like learning don't you?

Alex: Yeah I do.

Janette: And he's come on leaps and bounds since he went to Eastbrook, he's

really come on well. He's just had a letter today to see if he wants to join the gifted and talented maths class.

Alex: Yeah well everyone in... everyone in set 1 in maths got given that didn't they?

Janette: Yeah (?) just up from the SATs because there's a SATs this year.

Ken: Right.

37

A being different to other children – need to be taught social skills

531-555

Janette: So you keep telling him the same thing over and over again.

Alex: And suddenly...

Janette: I mean **he would run downstairs with no clothes on at all if he heard the door**, which is quite funny when they're 5 or 4.

Ken: Yeah [laughs].

Janette: When they're doing it at 8 and 9 it's not so funny anymore.

Ken: No it's not [laughter].

Alex: And then it just clicked.

Janette: And we kept telling him he couldn't do that, couldn't do that and over night he went from this around naked to being I'm not even allowed in the bathroom when he was in the bathroom, you know. He just totally changed to the opposite end of the spectrum didn't you?

Alex: Yeah.

Janette: And he doesn't do that anymore.

Alex: No.

SELF PERCEPTION – VIEW OF SELF

13

Co morbidity –

ADHD

14

Single-mindedness

122-151

Alex: I can get... I can get hyperactive some... I can get slightly like that sometimes if um if physical... if physical I can sometimes get over excited, not hyperactive, over excited sometimes.

Janette: But you know now yourself when you're getting over excited don't you?

Alex: Yeah

Janette: And he normally will say I'm getting over excited, I'm going to go to my room for a bit. And he goes and he chills out.

Ken: Excellent.

Janette: And you know he tends, he's still very independent and he doesn't need entertaining, he entertains himself. He's never been a child who needed entertaining as such because he likes his own company don't you?

Alex: Erm.

Janette: And he reads an awful lot.

Ken: Erm, so um...

Alex: I was actually reading when you knocked on the door mum.

Janette: Oh.

23

Strategies to help

242-254

Alex: That's very good because at school, at school the teachers tend to like me because **I've got good manners**... well according to them I've got good manners.

Janette: Yeah.

Alex: That's something that they... that's something that teachers seem to like about me a lot because um at the parents evening they tend to say that I've got good manners...

Janette: They do.

Alex: yeah.

Ken: So it's changed, did it have an impact... is Alex an only child or...?

Janette: Yes he's an only child.

Ken: So basically you've answered that really, it changed the way that you like you know like approached him from the point of view of his...

PERCEPTION OF WORLD – PEOPLE UNDERSTANDING OF THEM

65

A perception of world – black /white terms

1085-1126

Alex: Even now I have... even now I have um some Asperger see moments do come...

Janette: Oh yeah you still have your Aspe moments.

Alex: Yeah, I mean year 8 um I had Miss... oh I was going to say the name, I shouldn't have done that.

Janette: It doesn't matter.

Ken: It doesn't matter.

Alex: Alright, um oh doesn't it matter then unless I'm saying something like I don't like them or something?

Janette: Yeah.

Alex: Alright well Miss was my um art teacher in year 8 and she had a few problem children, well you know naughty children in there who were... so and I felt sorry for her and the Head of Art was always, well she'd go in and she'd complain to Miss about how the class was... and she'd you know all sorts of... I just didn't like the way she seemed to be as it were horrible to Miss and one day after art, I think it was a bit silly of me now, but **I just went up to her and asked why are you always so mean to Miss and she shouted me out of the art corridor.**

Janette: [Laughs].

Alex: I mean most people I suppose wouldn't have um well thought not to say that but...

Janette: Yeah you would say it.

Alex: It needed saying as far as I was concerned. There's quite a black and white thing with me about right and wrong, that's why I want to be a solicitor actually, that's one of the main things. I've also been told by people that I'd be a good solicitor. **I can see things in black and white, not to say that I'm colour blind,** I can see colours, I'm not colour blind [laughs].

APPENDIX 15: THEMATIC ANALYSIS STAGE 2: SUMMARY OF INITIAL CODES – JANETTE & ALEX

- 1
Parent suspicions
A14-28
- 2
A perception of affection
A30-37
- 3
Role of professional – parents not being listened to
- 4
Transition – role of professionals
A40-49
- 5
Role of professionals – this is what professionals can do for you
A61-69
- 6
Mum the expert
- 7
Role of professionals – not listening
- 8
Impact of diagnosis - medication

A70- 87
- 9
Role of professional – impact of diagnosis
- 10
Mum the expert
- 11
Role of professionals – parents not being listened to

A91- 104
- 12
Strategies to help – diet
A106-120
- 13
Co morbidity –
ADHD

14
Single-mindedness

A122-151

15
Mums feelings – impact of diagnosis
16
Self perception of needs

A156-173

17
This is what professionals can do for you – impact of diagnosis

18
Mum the expert

A174-187

19
Impact of diagnosis
A188-201

20
Impact of diagnosis – strategies to help
A203-217

22
Mum the expert - impact of diagnosis

A219-240

23
Strategies to help
A242-254

24
Dads perception – strategies to help
A264-301

25
Impact of diagnosis on family – dad
A303-336

26
Education – mums fight to get additional support
A346-387

27

Transition – infants

28

Juniors – support

A346-387

29

Struggle to get support

A386-396

30

Quality of support – understanding – negative perceptions of class teacher

A399-413

31

A dislike of class teacher

A403-423

32

Training and knowledge / understanding of A needs – negative experiences

A425-450

33

Quality of support

A455-464

34

Mum the expert – strategies to help

A466-484

35

A rights to education and support

A486-497

36

A experiences of learning

A499-525

37

A being different to other children – need to be taught social skills

A531-555

38

Independence – travel

A562-570

39

Transition to secondary

40

Bullying
A575-590

41
Strategy to help – travel to school – support from parent support group
A592-621

42
Mum the expert
A625-632

43
Mums aspirations – feelings
A639-647

44
Support for mum

45
A - Understanding of diagnosis

46
Impact of medication

A669-684

47
Strategies to support
A686-697

48
Relationships – friends
A707-746

49
A perception of diagnosis – what does it mean?
A748-782

50
Impact of diagnosis on education
A783-802

51
Strategy to help – intervention – impact on education

52
Relationships – bullying – strategy to cope
A803-841

53
Impact of support – practical implication

A843-860

54

Impact of support – understanding of needs by teachers

Inclusion

A864-879

55

Impact of support – strategies to help

56

Impact of support – bullying

57

Training and knowledge – being listened to

A882-903

58

A awareness of being different to peers

59

Sources of motivation – academic abilities

A905-927

60

Impact of support – time

A931-942

61

Impact of support – supply teacher not understanding – source of anxiety for A

A944-973

62

A aspirations

A981-1033

63

Mum the expert -transition

A1035-1068

64

Support – impact of diagnosis

A1072-1081

65

A perception of world – black /white terms

A1085-1126

APPENDIX 16:
THEMATIC ANALYSIS STAGE 3 – COMBINING CODES TO FORM
SUMMARY OF THEMES AND SUB-THEMES FROM ALL INTERVIEWS

THEME 1- PARENTS EXPERIENCES

MUMS JOURNEY

1. MUM SUSPICIONS
2. MUM THE EXPERT
3. MUMS NOT BEING LISTENED TO
4. MUM ADVOCACY FOR SON
5. MUMS JOURNEY (FEELINGS):
 - MUMS DETERMINATION
 - MUMS FEELINGS – GUILT
 - MUM BEING BLAMED

DADS JOURNEY

1. DADS SUSPICIONS
2. DAD THE EXPERT
3. DADS ADVOCACY
4. DADS SUPPORT
5. DADS JOURNEY
 - HE'S LIKE ME (GENETIC LINK)

PARENTAL INVOLVEMENT

1. BOND BETWEEN PARENTS AND SON
2. PARENTS BEING JUDGED
3. LESSONS LEARNT
4. NOT BEING LISTENED TO
5. PARENTAL FEELINGS
6. GENETIC LINK
7. ATTACHMENT THEORY

PARENTAL ASPIRATIONS

1. HIGH ASPIRATIONS
2. LOW ASPIRATIONS
3. WORRIES ABOUT FUTURE
4. SUPPORT REQUIREMENTS
5. TRANSITIONS

IMPACT OF DIAGNOSIS ON FAMILY

1. MUM – RELIEF
2. MUM – ANXIETY – LIFELONG CONDITION
3. MUM – MENTAL HEALTH AND WELL BEING – NOT TO BLAME
4. DAD- WHAT WILL HAPPEN IN FUTURE
5. EXPERIENCES OF SIBLINGS
6. SUPPORT FOR PARENTS – COMING TO TERMS WITH DIAGNOSIS
7. SUPPORT FOR SIBLINGS
8. FAMILY SUPPORT

THEME 2 – EDUCATION EXPEREINCES

IMPACT OF DIAGNOSIS ON EDUCATION

1. EDUCATION SUPPORT-PARENTAL REQUEST FOR STATEMENT
2. TIME TO GET STATEMENT
3. FIGHT TO GET STATEMENT – NEEDS RECOGNISED
4. APPROPRIATE SPECIALIST HELP
5. TRIBUNUALS – LEGAL FIGHT – RIGHTS

SCHOOL AND SUPPORT

1. SCHOOL PERCEPTIONS – NAUGHTY CHILD
2. INAPPROPRIATE SUPPORT
3. QUALITY OF SUPPORT
4. QUANTITY OF SUPPORT
5. FLEXIBILITY OF SCHOOL
6. IMPACT OF HAVING SUPPORT WITHDRAWN
7. STRATEGIES TO HELP
8. EXAM CONCESSIONS
9. CREATIVE TEACHERS
10. EDUCATIONAL OUTCOMES

ROLE OF PROFESSIONALS

1. RANGE OF PROFESSIONALS INVOLVED
 - POLICE
 - PSYCHIATRIST
 - FAMILY SUPPORT
 - TEACHERS
 - SOLICITORS
 - BARRISTERS
 - DOCTORS

- PSYCHOLOGISTS
- SPECIALISTS
- SOCIAL WORKERS
- HEALTH VISITORS
- LEA OFFICERS

2. RELATIONSHIPS WITH EACH PROFESSIONAL

3. TRUST IN PROFESSIONALS

4. 'WE KNOW BEST'

THEME 3 - YOUNG MENS EXPERIENCES

VIEW OF SELF

1. AWARENESS THAT DIFFERENT
2. SELF PERCEPTION - VIEW OF SELF
3. VIEW ON EDUCATIONAL OUTCOMES
4. SCHOOL – POSITIVE EXPERIENCES
5. SCHOOL – NEGATIVE EXPERIENCES
6. ASPIRATIONS
7. PERCEPTION OF WORLD – PEOPLE UNDERSTANDING OF THEM

RELATIONSHIPS

1. FRIENDS
2. MUM
3. DAD
4. SIBLINGS
5. SUPPORT WORKERS
6. PROFESSIONALS
7. SCHOOL
8. BULLIES

PERSONAL CHARACTERISTICS

1. LEARNING STYLES
2. EGOCENTRICITY – SINGLEMINDEDNESS
3. HUMOUR - FEELINGS
4. ANGER – FEELINGS
5. SOCIAL ACTING – MASQUARADING
6. SOCIAL ANXIETY
7. SOCIAL NAIVIETY
8. SOURCES OF MOTIVATION
9. CIRCUMSCRIBED INTERESTS
10. OBSESSIONS
11. MEMORY OF EVENTS

12. FANTASY VS REALITY
13. SURVIVAL STRATEGIES

BEHAVIOUR

1. THOUGHTS TO DESCRIBE BEHAVIOUR NOT FEELINGS
2. PLAYGROUND
3. CHALLENGING BEHAVIOURS
4. TRANSITIONS

COMORBIDITY – ADHD

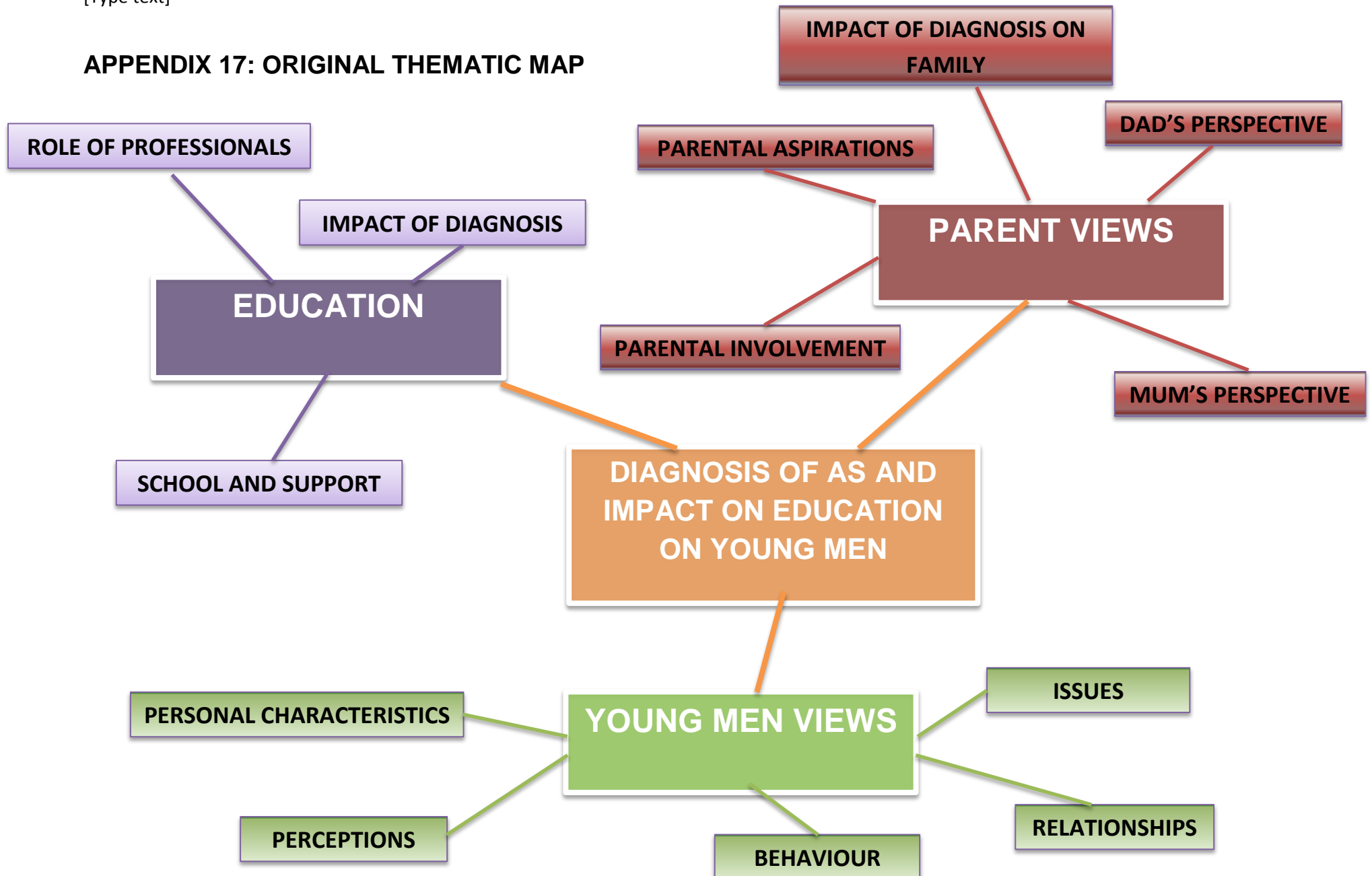
1. IMPACT ON BEHAVIOUR
2. MEDICATION AND IMPACT ON PUPIL

THEME 4 - ISSUES

1. IMPACT OF ADOLESCENCE
2. ADOLESCENCE AND BEHAVIOUR
3. PEERS PERCEPTION OF ASPERGER SYNDROME
4. PUPILS RIGHTS
5. RIGHTS – EDUCATION – SOCIAL CURRICULUM
6. SOCIETY – AWARENESS OF CONDITION
7. HUMOUR

[Type text]

APPENDIX 17: ORIGINAL THEMATIC MAP



APPENDIX 18:

KEY REFERENCES GENERATED FROM LITERATURE SEARCH:

Strand 1: Parents' experiences of the journey to obtain a diagnosis of AS for their son	Shu (2009) Quality of life of family caregivers of children with autism. <i>Autism</i> , Sage 13(1) 81-91
	Smith, Greenberg, Seltzer & Hong (2008) Symptoms and behaviour problems of adolescents and adults with autism: effects of mother-child relationship quality, warmth, and praise. <i>American Journal on Mental Retardation</i> 113(5) 387-402
	Ryan & Runswick-Cole K. (2009) From advocate to activist: mapping the experiences of mothers of children on the autism spectrum. <i>Journal of Applied Research in Intellectual Disabilities</i> 22, 43-53
	Sansostini F., Lavik K., & Sansostini J. (2012) Family experiences through the autism diagnostic process. <i>Focus on Autism and Other Developmental Disorders</i> 27(2) 81-92
	Goin-Kochel R., Mackintosh V., & Myers B. (2006) How many doctors does it take to make an autism spectrum diagnosis? <i>Autism</i> 10, 439-451
	Robert, Leblanc & Boyer (2014) When satisfaction is not directly related to the support services received: understanding parents' varied experiences with specialised services for children with developmental disabilities. <i>British Journal of Learning Disabilities</i> , early publication on-line. DOI: 10.1111/bld.112092
	Mackintosh V., Goin-Kochel R., & Myers B. (2012) "What do you like/dislike about the treatments you are currently using?" A qualitative study of parents of children with autism spectrum disorders. <i>Focus on Autism and Other Developmental Disorders</i> 27(1) 51-60
	Reed P. & Osborne L. (2012) Diagnostic practice and its impacts on parental health and child behaviour problems in autism spectrum disorders. <i>Archives of Disease in Childhood</i> 97, 927-931
	Brookman-Frazee, Baker-Ericzen, Stadnick & Taylor (2011) <i>Parent Perspectives on Community Mental Health Services for Children with Autism Spectrum Disorders</i> - Published online © Springer Science+Business Media, LLC 2011
	Lasser & Corley (2008) Constructing normalcy: a qualitative study of parenting children with Asperger syndrome. <i>Educational Psychology in Practice</i> 24(4) 335-346

	Stoner & Stoner (2014) Career disruption : the impact of transitioning from a full-time career professional to the primary caregiver of a child with autism spectrum disorder. Focus on Autism and Other Developmental Disabilities, early publication on-line. DOI: 10.1177/1088357614528798
Strand 2: Parents' experiences of their son's secondary education following the diagnosis	Camarena P. & Sarigiani P. (2009) Post-secondary educational aspirations of high functioning adolescents with autism spectrum disorders and their parents. Focus on Autism and Other Developmental Disabilities 24(2) 115-128
	Tobias A. (2009) Supporting students with autistic spectrum disorder (ASD) at secondary school: a parent and student perspective. Educational Psychology in Practice 25(2) 151-165
	Tobin, Staunton, Mandy, Skuse, Hellriegel, Baykaner, Anderson & Murin. (2012) A qualitative examination of parental experiences of the transition to mainstream secondary school for children with an autism spectrum disorder. Educational & Child Psychology Vol. 29 No. 1 75
	Whitaker (2007) Provision for youngsters with autistic spectrum disorders in mainstream schools: what parents say, and what parents want. British Journal of Special Education 34(3) 170-178
	Penney (2013) Qualitative investigation of school-related issues affecting individuals diagnosed with autism spectrum disorders and co-occurring anxiety and/or depression. Autism Insights 13(5) 75-91
	Alexander, Franks, Gardner, March, Paterson, Scott & Smith (2005) What Constitutes Effective Inclusion in Mainstream Secondary Schools for Pupils with ASD?
	Ryan S. & Runswick-Cole K. (2009) From advocate to activist: mapping the experiences of mothers of children on the autism spectrum. Journal of Applied Research in Intellectual Disabilities 22 43-53
	Camarena & Sarigiani (2009) Post-secondary educational aspirations of high functioning adolescents with autism spectrum disorders and their parents. Focus on Autism and Other Developmental Disabilities 24(2) 115-128
	Whitaker P. (2007) Provision for youngsters with autistic spectrum disorders in mainstream schools: what parents say, and what parents want. British Journal of Special Education 34(3) 170-178

Strand 3 : Young men's experiences of secondary education following the diagnosis	Humphrey & Symes (2010) Perceptions of social support and experience of bullying among pupils with autistic spectrum disorders in mainstream secondary schools. <i>European Journal of Special Needs Education</i> 25(1) 77-91
	Hill (2014) 'Some of it I haven't told anybody else': Using photo elicitation to explore the experiences of secondary school education from the perspective of young people with a diagnosis of Autistic Spectrum Disorder. <i>Educational & Child Psychology</i> Vol. 31 No. 1 79
	Carrington, S. & Graham (2001). Perceptions of school by two teenage boys with Asperger's Syndrome and their mothers: A qualitative study. <i>Autism</i> , 5(1), 37–48
	Connor, M. (2000) Asperger's Syndrome (Autistic Spectrum Disorder) and the self-reports of comprehensive school students. <i>Educational Psychology in Practice</i> , 16(3), 285–296.
	Hay & Winn (2005) Students with Asperger's Syndrome in an inclusive secondary school environment: Teachers', parents', and students' perspectives. <i>Australasian Journal of Special Education</i> , 29(2), 140–154
	Humphrey & Lewis. (2008) The views and experiences of pupils on the autistic spectrum in mainstream secondary school. <i>Autism</i> , 12(1), 23–46
	Tobias (2009). Supporting students with autistic spectrum disorder (ASD) at secondary school: A parent and student perspective. <i>Educational Psychology in Practice</i> , 25(2), 151–165
Strand 4: Young men's experiences of having a diagnosis of AS	McLaughlin & Rafferty (2014) Me and 'It': Seven young people given a diagnosis of Asperger's Syndrome. <i>Educational & Child Psychology</i> Vol. 31 No. 163
	Molloy & Vasil (2004) Asperger's syndrome, adolescence, and identity. Looking beyond the label. London: Jessica Kingsley Publishers
	Huws & Jones (2008) Diagnosis, disclosure, and having autism: an interpretative phenomenological analysis of the perceptions of young people with autism. <i>Journal of Intellectual and Developmental Disability</i> 33(2) 99-107
	Portway & Johnson (2005) Do you know I have Asperger's syndrome? Risks of a non-obvious disability. <i>Health, Risk & Society</i> , 7(1): 73–83
	Carrington, Papinczak & Templeton, E. (2003). A phenomenological study: The social world of five adolescents who have Asperger s Syndrome. <i>Australian Journal of Learning Disabilities</i> ,8(3), 15-21

	Carrington, Templeton & Papinczak (2003) Adolescents with Asperger's Syndrome and perceptions of friendship. <i>Focus on Autism and Other Developmental Disabilities</i> , 18(4), 211–218
	Howard, Cohn & Orsmond, (2006) Understanding and negotiating friendships: Perspectives from an adolescent with Asperger's Syndrome. <i>Autism</i> , 10(6), 619–627
	Shipman, Sheldrick & Perrin (2011) Quality of life in adolescents with autism spectrum disorders: reliability and validity of self-reports. <i>Journal of Developmental and Behavioral Pediatrics</i> 32(2) 85-89
	Huws & Jones (2013) 'I'm really glad this is developmental': Autism and social comparisons – an interpretative phenomenological analysis <i>Autism Sage</i>
	Humphrey & Symes (2010) Perceptions of social support and experience of bullying among pupils with autistic spectrum disorders in mainstream secondary schools. <i>European Journal of Special Needs Education</i> 25(1) 77-91
	Penney (2013) Qualitative investigation of school-related issues affecting individuals diagnosed with autism spectrum disorders and co-occurring anxiety and/or depression. <i>Autism Insights</i> 13(5) 75-91
	Tobias A.(2009) Supporting students with autistic spectrum disorder (ASD) at secondary school: a parent and student perspective. <i>Educational Psychology in Practice</i> 25(2) 151-165
	McLaughlin & Rafferty (2014) Me and 'It': Seven young people given a diagnosis of Asperger's Syndrome. <i>Educational & Child Psychology Vol. 31 No.163</i>
	Hill (2014) Some of it I haven't told anybody else': Using photo elicitation to explore the experiences of secondary school education from the perspective of young people with a diagnosis of Autistic Spectrum Disorder. <i>Educational & Child Psychology Vol. 31 No. 179</i>
	Huws & Jones (2013). 'I'm really glad this is developmental': Autism and social comparisons – an interpretative phenomenological analysis <i>Autism</i> 0(0) 1–7 sagepub.co.uk/journalsPermissions.nav DOI: 0.1177/1362361313512426 aut.sagepub.com

42 ARTICLES FOUND

APPENDIX 19

LITERATURE SEARCH – ARTICLES SELECTED TO REVIEW

Strand 1: Parents’ experiences of the journey to obtain a diagnosis of AS for their son	Ryan & Runswick-Cole K. (2009) From advocate to activist: mapping the experiences of mothers of children on the autism spectrum. <i>Journal of Applied Research in Intellectual Disabilities</i> 22, 43-53
	Sansostini F., Lavik K., & Sansostini J. (2012) Family experiences through the autism diagnostic process. <i>Focus on Autism and Other Developmental Disorders</i> 27(2) 81-92
	Leblanc R. & Boyer (2014) When satisfaction is not directly related to the support services received: understanding parents’ varied experiences with specialised services for children with developmental disabilities. <i>British Journal of Learning Disabilities</i> , early publication on-line. DOI: 10.1111/bld.112092
	Lasser & Corley (2008) Constructing normalcy: a qualitative study of parenting children with Asperger syndrome. <i>Educational Psychology in Practice</i> 24(4) 335-346
	Stoner & Stoner (2014) Career disruption : the impact of transitioning from a full-time career professional to the primary caregiver of a child with autism spectrum disorder. <i>Focus on Autism and Other Developmental Disabilities</i> , early publication on-line. DOI: 10.1177/1088357614528798
Strand 2: Parents’ experiences of their son’s secondary education following the diagnosis	Stoner & Stoner (2014) Career disruption : the impact of transitioning from a full-time career professional to the primary caregiver of a child with autism spectrum disorder. <i>Focus on Autism and Other Developmental Disabilities</i> , early publication on-line. DOI: 10.1177/1088357614528798
	Tobin, Staunton, Mandy, Skuse, Hellriegel, Baykaner, Anderson & Murin. (2012) A qualitative examination of parental experiences of the transition to mainstream secondary school for children with an autism spectrum disorder. <i>Educational & Child Psychology</i> Vol. 29 No. 1 75
	Alexander, Franks, Gardner, March, Paterson, Scott & Smith (2005) What Constitutes Effective Inclusion in Mainstream Secondary Schools for Pupils with ASD?
	Whitaker P. (2007) Provision for youngsters with autistic spectrum disorders in mainstream schools: what parents say, and what parents want. <i>British Journal of Special Education</i> 34(3) 170-178

Strand 3 : Young men's experiences of secondary education following the diagnosis	Hill (2014) 'Some of it I haven't told anybody else': Using photo elicitation to explore the experiences of secondary school education from the perspective of young people with a diagnosis of Autistic Spectrum Disorder. Educational & Child Psychology Vol. 31 No. 1 79
	Tobias (2009). Supporting students with autistic spectrum disorder (ASD) at secondary school: A parent and student perspective. Educational Psychology in Practice, 25(2), 151–165
	Alexander, Franks, Gardner, March, Paterson, Scott & Smith (2005) What Constitutes Effective Inclusion in Mainstream Secondary Schools for Pupils with ASD?
Strand 4: Young men's experiences of having a diagnosis of AS	McLaughlin & Rafferty (2014) Me and 'It': Seven young people given a diagnosis of Asperger's Syndrome. Educational & Child Psychology Vol. 31 No. 163
	Huws & Jones (2008) Diagnosis, disclosure, and having autism: an interpretative phenomenological analysis of the perceptions of young people with autism. Journal of Intellectual and Developmental Disability 33(2) 99-107
	Huws & Jones (2013) 'I'm really glad this is developmental': Autism and social comparisons – an interpretative phenomenological analysis Autism Sage
	Huws & Jones (2013). 'I'm really glad this is developmental': Autism and social comparisons – an interpretative phenomenological analysis Autism 0(0) 1–7 sagepub.co.uk/journalsPermissions.nav DOI: 0.1177/1362361313512426 aut.sagepub.com

15 ARTICLES SELECTED

Appendix 20: REFLECTIVE DIARY - EXCERPTS

Reflections on interview with Ben:

What is Ben's experience of being at school at that time?

Ben said that he wanted to do what he wanted to do all the time and did so.

Ben did what he wanted to do regardless of any control internally (SELF) or externally (environment -teachers etc.)

Ben refers to quote getting really bad - does this mean that he is relating to the experience as opposed to himself, meaning that his behaviour was bad, but not him as a person.

I need to reflect on the above in order to guard for being over judgemental and categorising Ben's behaviour is bad.

The general issue here relating to how Ben experienced difficulty talking emotionally about his behaviour and use his thought processes to convey feelings i.e. talking about his behaviour in a logical and analytical way.

On reflection, it is clear that I need to concentrate on what the young men are saying to me. I can only gain what they are giving me from their understanding of their world and experiences of school life.

Mother worked well in clarifying any questions posed by myself and did not impose her perception of Ben's response but explained these to Ben, which helped me to clarify that I had understood what Ben was saying. It certainly felt to me that mother was the expert in this situation.

Ben also talked about having friends and that he enjoyed going to school.

Ben also talked about his attention deficit hyperactive disorder and how this had affected his behaviour. This led me to reflect on conceptualisations of Neurodiversity in that Asperger syndrome really exist by itself. Comorbidities exist, including ADHD, dyslexia, and dyspraxia.

The issue of bullying seems to be a frequent occurrence in Ben's life however does talk about having a 'safe place in the playground where all his friends are'.

Being bullied in the playground something that I experienced as a young black child. I responded to this by fighting back. Ben seems to have done the same, which is got into a lot of trouble and has led to periods of exclusion.

It was moving to hear mother talking about her guilt and fear that was all her fault that Ben was the way he was. She talked about how she had a good relationship with the school and has been actively involved in her capacity school governor. This is enabled her to be able to influence school decisions regarding excluding pupils like Ben who are not being seen as being wilfully disruptive.

I noted that many of the mothers interviewed referred to being perceived as having poor parenting skills and query whether I myself have considered parents in a similar light.

As a practitioner researcher these interviews have highlighted issues regarding adolescence, peer pressure playground and bullying in the school that EPs need to be proactive on promoting positive strategies to effect change.

I need to be aware that what I'm trying to do is to represent my interpretation of what mothers and young wingers saying to me, so that I'm not saying this is what it's like to have Asperger syndrome but saying this is my reading or my interpretation of what it is like to have Asperger syndrome.

Interview with Janette and Alex:

I reflected on mothers comment upon gaining the diagnosis that she changed her way of nurturing Alex from overindulging him to training him in developing social skills ,“train him like a dog” was used by mum in a loving way but was quite moving to hear. As was mothers comment that “she was devastated” upon receiving the diagnosis.

From the mothers' stories and on interviewing some of the fathers' it appeared to me that many had similar traits to their sons. Further those mothers' were very supportive of their husbands who often clashed with sons. This must have been difficult and put a tremendous strain on the relationships in the family. This highlights the need for support for the whole family including siblings.

Also appeared to me that the diagnosis was not about the child but the whole family and indeed Alex is mother talks about her and the rest of the family receiving the diagnosis.

Key messages gained on reflection from interviews include the following:

Attachment - Mother & son bond - Quest to ensure son's needs are met - Naturally protective of child - Will fight for son's well-being - Taking on professionals - Self research - support from others - Marital discord - Impact on siblings - Mum's role as a trainer - Support for family.

Felt the mum's role as a co-researcher was excellent and we worked well together.

On reflection, I feel that I am gaining an invaluable insight into the experiences of mothers and their sons through this research. I'm also aware that I am coming from a male perspective in attempting to understand mothers' experiences.

I was struck by mother's final comment which was 'if you meet parents who are newly diagnosed told them that there is much hope and to not despair as I did'

This highlighted to me the impact that the diagnosis is had on the whole family and of the need for all professionals working with the family to recognise this. Support needs to be offered to parents and very importantly siblings were often not considered in any support package.

In all of the interviews with mothers, I became aware of their keenness to tell me their story in appreciation that I was an experienced practitioner who understood the nature of their journey.

Reflections on Interviewing Philip:

an issue that occurred to me on reflection, was that some children are better at certain things than others. Young people Asperger syndrome need flexible thinking by educationalist to help them maintain their motivations to stay within a relatively rigid system in secondary education. It struck me that we have expectations that all children will achieve across-the-board. We have to make everyone equal which is in fact a misnomer. Example, a parent been told that their son is very good English, but not in maths could be seen negatively by that parent when really celebration should be on the success achieved. We have an expectation in education in providing “a rounded” experience for all children. Not all children can achieve this and for young people with Asperger’s syndrome many stressors have occurred as a result of this perception. More creativity is therefore required in adapting the curriculum to meet the needs of students with Asperger syndrome.

Throughout the research I found that taping the consultations with my supervisor and recording my thoughts proved invaluable in facilitating my ability to reflect on my role as a researcher.

On reflection, I have realised the need to analyse all the data the matter how time-consuming, as was important not to cherry pick data without gaining an

overall feel of the findings. This also helped to maximise my understanding of the methodology and data analysis in order to be transparent as a researcher.

This research has helped me to appreciate that exploring the views of mothers and sons. I need to focus on:

This is who these people are

This is how they behave.

This is how they view the world.

These are things that they say.